DOCUMENT RESUME

ED 323 692	EC 232 120

AUTHOR	Knoll, James A.; And Others
TITLE	Family Support Services in the United States: An End of Decade Status Report.
INSTITUTION	Human Services Research Inst., Cambridge, MA.
SPONS AGENCY	Administration for Children, Youth, and Families (DHHS), Washington, D.C.
PUB DATE	Feb 90
CONTRACT	90DD0156
NOTE	320p.
AVAILABLE FROM	Human Services Research Institute, 2336 Massachusetts Ave., Cambridge, MA 02140 ($15.00).
PUB TYPE	Reports - Research/Technical (143) -- Tests/Evaluation Instruments (160)
EDRS PRICE	MF01/PC13 Plus Postage.
DESCRIPTORS	Agency Cooperation; Community Programs; Delivery Systems; *Developmental Disabilities; Eligibility; *Family Programs; National Surveys; Needs Assessment; Parent Role; Social Services; State Legislation; *State Programs; Trend Analysis

ABSTRACT

The monograph examines the status and needs of state family support efforts over the last decade, based on interviews with 83 people in state Developmental Disabilities Councils and various state agencies. An introductory section provides an historical context for family support, presents a synthesis of state family support efforts, and delineates key components of appropriate family support systems including: (1) legislative mandate; (2) articulated guiding principles; (3) family focus; (4) parental control; (5) parent oversight; (6) flexible funding; (7) core services; (8) service brokerage; (9) interagency collaboration; (10) inclusive eligibility; (11) statewide scope; (12) Medicaid policy; (13) community centeredness; and (14) active outreach. The major portion of the document consists of profiles of each state, which typically include information on name and nature of program, date of implementation, administering agency/contact person, number of families served, eligibility criteria, services covered and allowable expenditures, limits on benefits, current funding level, background, program structure, implementation issues, Medicaid policy, related efforts, evaluation, future directions, and lessons learned. Appended are the phone interview guide and associated letter. Contains 28 references. (DB)

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Family Support Services in the United States: An End of Decade Status Report

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FAMILY SUPPORT SERVICES IN THE UNITED STATES: AN END OF DECADE STATUS REPORT

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FEBRUARY, 1990

ACKNOWLEDGEMENTS

The complex nature of this effort to gain a perspective on the development of family support policy at both the state and national level required the assistance, patience, and goodwill of individuals throughout the country. First of all, the authors are immensely grateful to the 83 people in state Developmental Disabilities Councils and various state departments who took time away from their busy schedules to be interviewed and then to review our efforts to capture what they told us. These people are in a very real sense co-authors of this report.

We would like to also thank the parent training groups in Ohio, West Virginia, and Missouri who acted as a sympathetic sounding board for our ideas about the necessary components of a comprehensive family support system. Their reactions helped keep us on focus throughout the preparation of this report.

At Human Services Research Institute Paul Nurcynski, Lasell Whipple, and Lissett Rodriguez did a marvelous job of processing all of the information contained in this report and putting it in a readable format.

Preparation of this report was supported with funds from the Administration on Developmental Disabilities, Office of Human Development Services, U. S. Department of Health and Human Services under grant number 90DD0156. All opinions expressed herein are solely those of the authors and do not reflect the position or policy of the Department of Health and Human Services

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FAMILY SUPPORT IN THE UNITED STATES: AN OVERVIEW

The present study was designed as one aspect of a larger effort to provide states with technical assistance related to the development of a systematic approach to family supports. Discussions with policy makers, providers, and parent groups around the country and a review of the literature crystalized the need to develop an up-to-date base of information on the current status of state family support efforts before launching into an intensive technical assistance effort. This introductory section provides an historical context for family support, provides a synthesis of state family support efforts, and concludes by delineating some of the key issues surrounding the development of family support. This section is followed by a description of the family support activities in each state

FAMILY SUPPORT IN THE 1980s: AN EMERGING PERSPECTIVE

The 1980s have been the decade in which the family agenda finally made it onto center stage in state and national policy deliberations. As the decade progressed terms like "day care," "parental leave," and "the mommy track" appeared with increasing frequency in the daily press and on the evening news. Issues related to the relationship between the individual, the family, and the state became some of the major concerns of the electorate. As family concerns in general gained prominence, the special concerns and needs of families of people with disabilities emerged as central issues in the debate over this nation's policy on services for people with disabilities. If events in the 1980s have helped to define the agenda, the policies of the 1990s will determine whether the agenda is translated into concrete supports and expanded services.

For almost a quarter of a century services to people with disabilities -- and particularly services to people with developmental disabilities have been in a seemingly endless state of flux. Central to this process has been the transformation of the system of services from institutions to communities. With terms like deinstitutionalization, normalization, group home, least restrictive environment, continuum of services, home-like environments, or community-based services characterizing the direction, change has been the status quo for the entire career of most workers now in the field. These changes, however, have been made somewhat haltingly and self-consciously. For while it was relatively easy to critique the short comings of institutional services, arriving at the essential components of a system of services in the community has proven has proven somewhat more problematic. Self-scrutiny, rooted in a concern that the abuses of the past not be replicated, have led people with disabilities, parents, advocates, service providers, and researchers to challenge each new approach. While a particular model of service might be hailed at one moment as "the answer" for providing normalized humane services, it is likely, in short order, to be criticized for embodying some of the limits on individual growth found in earlier modes of service.

A major focus of the initial efforts to reform services was development of small programs located in communities. The literature of the 1970s speaks of a need for services to develop "homelike environments" in "culturally normative settings" which are "age-appropriate." For nearly a decade the field of developmental disabilities struggled with determining the ramifications of this kind of rhetoric. It seemed obsessed with resolving issues like "What is the appropriate size for a homelike environment?" "What does a culturally normative setting look like?" or "How many teddy bears can an adult woman have in her bedroom before it begins to look as though it is not an age-appropriate setting?"

The need to grapple with these and other issues of normalization were fundamentally about balancing the competing demands of a person's special needs, the requirements of an agency managed programs, and the individual's basic human needs and rights. In the 1980s the rubric of "community integration," defined as the right of all people with disabilities to have full membership in communities, enabled an increasing number of people in the field of developmental disabilities to begin to appreciate the fatal flaw in this balancing act (see Smull, 1989). What is emerging from this process is a growing consensus that service providers should focus their efforts not on creating "settings" which approximate culturally normative living arrangements but rather on supporting individuals in neighborhood schools, real jobs, and in their own homes.

Tracking a Decade of Change

Central to this changing awareness have been efforts to re-examine and redefine the relationship between the public sector and families of children and adults with disabilities and between such families and formal helping networks. One of the earliest critics of the emerging pattern of "community-based" services was Skarnulis (1979) who called for policy makers and providers to stop "supplanting" the family and start supporting it. The wisdom of this observation, although not lost on some administrators and providers concerned with family support, has taken a decade to influence the national trends in the field.

The "support not supplant" philosophy coupled with changes in the political and economic climate ushered in a period of unparalleled interest in the development of services for people with disabilities within the family home. On the federal level the terms "family support," "family-centered," and "community-based" pervaded the requests for proposals and conference agendas of almost every relevant agency (Administration on Developmental Disabilities, 1988; Koop, 1987; Nelkin, 1987; Shaffer & Cross, 1989). This was accompanied by the development of a variety of new federal programmatic initiatives, most notably waivers and other recent Medicaid options, which were designed specifically to provide for services to people with disabilities in the family. As previous research in the field and the findings of this report clearly demonstrate these developments on the national stage have been at least equalled at the state and local level.

- Researchers have begun to shift their focus from a concentration on disability as a source of stress within the family to an increased emphasis on the impact of various support strategies on families (see for examples Dunst, Trivette, & Deal 1988, Gallagher & Vietze, 1986; Knoll & Bedford, 1989; Singer & Irvin, 1989).
- A series of publications appeared over the decade that tracked the gradual development of family support policy and outline the options available to policy makers (Agosta & Bradley, 1985; Cohen, Agosta, Cohen & Warren, 1989; Bates, 1985; Bird, 1984; Braddock, Hemp, Fujiura, Bachelder, & Mitchell, 1990; Taylor, Lakin, & Hill, 1989).
- During the 80s, there were several efforts to make the intricacies of financing family support and home care accessible to parents and providers (e.g., Ellison, Bradley, Knoll, & Moore, 1989; Gaylord & Leonard, 1988)

- A number of publications provided parents with readily accessible information to aid them in supervising services within the home (Goldfarb, Botherson, Summers, & Turnbull, 1986; Jones, 1985 Kaufman & Lichtenstein, 1986).
- These were accompanied by guides to assist parents in actually influencing the development of service in their community (Bronheim, Cohen, & Magrab, 1985; Hazel, Barber, Roberts, Behr, Helmstetter, & Guess, 1988).
- A final distinct group of publications synthesized the developing trends in family support and identified the values or principles that should guide public policy towards people with disabilities and their families. Most of these efforts were intended to provide advocates with a clear agenda to organize efforts at systems change (e.g., United Cerebral Palsy, 1987). Some reports emerged as parts of federally sponsored projects aimed at the needs of children with severe disabilities (Center on Human Policy, 1987) and with special health care needs (Maternal and Child Health, 1988).

Defining Family Support

This growing body of literature can be a bit daunting. What is compelling is how, over the course of the 1980s, a unifying core of principles related to support of families of people with disabilities has emerged. Central to these principles is the knowledge that every family is different. No two families or two persons with disabilities are exactly alike. This means that the supports a family may need can differ from those needed by other families. This has led many to conclude that the "support" in family support should be defined by the family. As such, a family support program must be prepared to provide ***whatever it takes to maintain and enhance the family's capability to provide care at home.***

Family support cannot be construed as a single service (e.g., respite or a stipend), but rather as a flexible and varied network of supports that can accommodate individual family concerns. Moreover, to be most effective family supports must be administered in ways that enable and empower families and persons with disabilities to maintain or regain control over their own lives and the lives of their family. It seems central to achieving this goal that the supports offered to families must be administered so that they are **family centered, culturally sensitive, community-centered, and well-coordinated**.

Family centered approaches. Many of the family oriented services that have emerged in the past decade have embraced a "family-centered" philosophy. Yet, most state and local systems are only just coming to grips with the implications of this concept. As used here, the notion of "family centered" includes three basic premises.

- **Services should enable families to make informed decisions.** Service models must be founded on the presumption that families are potentially capable and willing to make responsible decisions; families want the best for their children.

  Of course, there are limits to the emotional, physical and financial resources of parents and their expertise. When first confronted with the reality of a disability, many family members have little understanding of what overall needs they or their child will have. Moreover, even as time passes, some families are unable or unwilling to accept an empowered role. Yet the absence of needed skills among some or the reluctance of others does not justify the substitution of professional judgement in every case.

- **Services should be responsive to the needs of the entire family.** Within a family systems framework, the family is viewed as an interacting, reacting system that is delicately balanced and struggles to maintain that balance. A change or problem in one aspect of the system affects the entire system. Thus, family support practices cannot be directed solely at the needs of the child. Rather, supports should be available to other family caregivers, with the intent of enhancing the family's overall capacity to provide care.

- **Services should be flexible enough to accommodate unique needs.** No two families, with or without children with disabilities, are alike. Considerable variation exists regarding disability types and severity, family characteristics and resources, and family perceptions regarding the caregiving situation. Moreover, these factors do not remain the same, but change over time. This means that responsive programs must permit a wide array of supports (i.e., multiple support options) and must encourage each family to select those that are most appropriate.

Culturally sensitive approaches. No single approach to supporting families is likely to work with all families. Differences in family type, culture, income and geographic location call for diversity in the approaches undertaken. For instance, the needs and preferences of families living in urban areas may differ markedly in from those living in more rural areas. To be most effective, support services must be consistent with the culturally based preferences of individual families. This holds true regardless of the number of families sharing a particular belief system or the degree of difference between the dominant and minority cultures. Further, the same principle can be applied to areas other than cultural differences such as race, geographic diversity (e.g., urban vs. rural) or socioeconomic status.

Community-centered approaches. Historically, the primary response to disability has been to provide services through the public sector; that is, through some type of government program. Present practice, however, increasingly relies on alternatives available through generic community services, the private sector, or within informal helping networks to complement publicly funded specialized services. In some part, this shift is based on the belief that supports are most effective and least costly when their source is closest to the family, both geographically and personally.

Many supports can and should be available through informal means or from the private sector (e.g., extended family, employer benefits, private health insurers). In fact, by focusing on governmental solutions exclusively, existing helping networks may inadvertently be displaced or other potential sources of support may never be utilized.

Extended family, friends, neighbors and others in the community can all have a positive influence on families. Such support can play a key role in easing the day-to-day challenges experienced by families. Likewise, the potential utility of supports offered through more formal private sector structures should not be ignored. Every community contains businesses or organizations that may prove helpful to families. For instance, local building contractors may find ways to make a home barrier free. Day care operators, with some specialized training, may be persuaded to serve children with severe disabilities; and employers can tailor benefits packages to satisfy individual family needs.

Comprehensive and well coordinated approaches. Numerous programs presently exist for providing services to children with disabilities and their families under the auspices of: 1) state disabilities and health agencies; 2) Developmental Disabilities Planning Councils; 3) the public educational system as mandated by the Education of All Handicapped Children Act (P.L. 94-142) and subsequent amendments related to early intervention (P.L. 99-457); 4) university programs supported by federally financed demonstration projects and/or through a University Affiliated Facility (UAF) or Program (UAP); and 5) the private sector including employers, private businesses, charitable foundations or specialty care settings, such as hospitals, that offer a range of family supports. Although these programs vary as to target population and services provided, they are part of the potential network of supports that could be used to benefit children with disabilities and their families. The challenge facing service practitioners is to weave these potential sources of support together in a manner that assures: 1) the child with disabilities receives needed habilitative or health related services; 2) family members receive the supports they need to enhance their capacity to provide care and to function as a family; and 3) potential community centered helping networks, outside the public domain, are utilized to the full extent feasible.

For every family need or preference, a government service need not be called upon in response. As we described earlier, there is great value to developing other sources of support within private businesses or among extended family and friends.

As states embrace a greater role in supporting families, their actions should not replace existing community helping networks or keep them from developing. In fact, in developing state policy, just the opposite should be done. Built into any approach to supporting families must be ways to utilize what already exists in the community.

Even with such positive efforts, however, we understand that existing private or informal community helping networks alone are not likely to meet the range of complex needs of children with disabilities and their families. Public funds and resources will continue to be needed. For example, children with severe physical limitations or chronic illnesses require the services of specialized professionals. Likewise, their family members need formalized supports that are not typically available within generic community services, such as planning for the future, disability related information and referral, or a support group made up of parents with similar experiences.

In the final analysis, perhaps the major contribution the public sector can make to families is to provide an environment in which families are valued, parents are seen as the greatest resource available to their children, and where resources are committed to supporting and encouraging these values. This study is an effort to explore the degree to which this perspective has taken root and has grown in the United States over the last few years.

METHODOLOGY

The problems in attempting to use reviews of family support developed only a few years ago underscore the often tentative and embryonic nature of these efforts in the United States. Each new fiscal year brings substantial change to the depth and breadth of family support programs around the country. Though much of the change is positive and reflects expansion, many programs no longer exist because they were pilot projects that did not become permanent. Further, many family support initiatives are not firmly established by legislative mandate and therefore, while they may continue, are susceptible to the vicissitudes of the state budgetary process.

It should be noted that the compartmentalization of family support and the lack of interagency collaboration are constraints to developing a comprehensive overview of each states commitment to family support. In two earlier projects we found that families encounter a major challenge when they seek out assistance (Knoll, 1989; Agosta & Knoll, 1988). Specifically, we found that families of children with a developmental disability may technically be eligible for some form of assistance from some or all of the following agencies in their state: health, Maternal and Child Health, Title V, social service, mental health, retardation, child protection, education, early intervention, pilot projects funded by the state developmental disabilities council, and others. These agencies may have complementary or even potentially duplicative programs. Unfortunately, no state has taken a comprehensive interagency approach to family support in a effort to maximize access to these resources. As a result, knowledge about services is often limited to people working in a discrete program. This leads to a situation in which a family may be eligible for a program but never hears about it because the primary contact is with providers who are involved with another state department and know nothing of benefits available outside that funding stream. Similarly when issues of program design emerge, a lack of knowledge about the full range of potential family support strategies leads to situations in which one state department may grapple with implementation issues that were long ago resolved by another department. Some of the earlier efforts to describe state family support practices suffered from this categorical limitation. That is they may have been very thorough in describing efforts funded under the state's developmental disabilities agency but failed to take into account significant related efforts in other state departments.

In an effort to address these limitations, a data collection instrument was designed to gain a thorough description of the full range of efforts in family support in each state. The data collection strategy was a phone interview and a "snowballing" approach to sampling in which each informant was asked to nominate other knowledgeable persons to be interviewed. Using this approach, data was collected until either no new subjects are identified or no new information is obtained.

The point of entry into each state was the state Developmental Disabilities Planning Council. The role of the council as defined by law and the leadership which many of them have exerted in the area of family supports suggested that council staff should be able to provide us with an overview of each state's efforts and contacts in the relevant state departments. At the end of May 1989, a letter was sent to the executive director of each council explaining our effort and asking them or another staff person to either make an appointment some time in June, July, or August for a phone interview or direct us to another person in the state who could provide us with an overview of family supports (see Appendix A). A second letter was sent to any council that did not reply by June 10th. If no response was received to this second inquiry by June 25th a phone call was made to set up an appointment or identify an alternate informant. As a result of this process, interviews were scheduled for all 50 states (we were unsuccessful in securing a contract in the District of Columbia).

A field test of the interview guide was conducted between June 12th and 23rd. Based on this test, the interview protocol was revised and, because the interviews took substantially longer than we originally envisioned, we cut back on some of the content. The revised interview form (see Appendix B) asked the informants to describe the major aspects of their state's family support efforts. The instrument is made up of 46 items in the following categories: general background, funding level, number of families served, eligibility criteria, administrative practices, programmatic practices, level of family control, implementation problems, program effectiveness, informant's evaluation of the program, related efforts in the state, efforts at service coordination, state Medicaid policy, interagency collaboration, generic services/informal supports, future directions, lessons learned thus far, and suggested contact persons for further information about family support efforts. The interviews ranged in length from ½ to 4 hours and averaged to about 1½ hours.

In most states the first interview was followed by a second call to the initial informant. In 33 states the first interview was followed with an additional interview with some other person associated with services in the state who was able to fill in any gaps remaining after the first interview. A total of 83 individuals were interviewed between June 15th and September 15th 1989 to collect the information for this study. Draft descriptions of each state's family support practices were prepared by October 1st and sent to all informants to review for accuracy. The informants were asked to submit all corrections by November first. The last set of corrections was finally received by December first.

The fifty state descriptions were analyzed to identify major implementation issues which appear in the following sections. While we were unable to achieve our original, ambitious goal of developing a comprehensive overview of all support efforts targeted to families of children with disabilities in the United States, we are able to report here on all efforts to provide support to families of children with a developmental disability through state departments of mental retardation or developmental disabilities and under state developmental disabilities councils. In addition, we have identified many efforts of other state departments on behalf of groups of children with other disabilities and their families. In this regard, the report provides a firm foundation for future efforts to compile a comprehensive guide to all family support activities.

RESULTS

Forty one states have developed programs with a specific focus on supporting families that are raising a child who has a developmental disability. These programs provided some service to at least 129,777 families during the last state fiscal year. An overview of these activities is found in Table 1. Many of these programs also provide supports for adults with a developmental disability in families. Given the history of limited services to families that raise their child with a disability at home and the distinct issues, such as personal autonomy which differentiate services for adults from children's services, we chose to concentrate on those aspects of state policy and practice that relate to children.

Spokes persons for the nine states that do not have a specific family support initiatives all contend that they provide in-home services and support to families through their typical community services, early intervention programs, or Medicaid waiver. However, when these programs are reviewed in

TABLE 1: SUMMARY OF STATE FAMILY SUPPORT ACTIVITIES - 1

STATE	NATURE OF SUPPORTS	TYPE OF PROGRAM	ELIGIBILITY CRITERIA	LIMITATIONS ON BENEFITS	ALLOWABLE SERVICES	FAMILIES SERVED	CURRENT FUNDING
ALABAMA	Respite	Pilot	Developmental Disability	10 days some service fees	Respite	65 in-home 378 at camp	$325,000.00
ALASKA	Services in Crisis	Pilot	Developmental Disability	None established some service fees	Respite, training, & attendant care	436 (30 in special crisis program)	$718,000.00
ARIZONA	1) Financial Aid	Budgeted	Developmental Disability	$4,800 per year with co-pay	Homemaker, home health aid, personal care, shelter assist., trans., chores, training, adaptations, repairs, renovations, nurse, equipment	177	Exact funding level unavailable
	2) Respite	Budgeted	Developmental Disability	Required co-pay	Respite	2153	$1,500,000.00
ARKANSAS	Financial Aid	Pilot	Child under 18, needs support to participate in community, returning from out of home or in transition, and lives in pilot areas.	$5,000 per year	Respite, special equipment, clothing, envir. modifications, communication aids, ramps/lifts, & other items not available or covered by other sources	36	$400,000.00
CALIFORNIA	Services	Mandated	Developmental Disability and under 18 years of age		Not limited to spec. medical & dental care, training, homemaker, camp, day care, respite, counseling, behav. mod., equipment, & advocacy	25000	$30,511,839.00
COLORADO	Financial Aid	Budgeted	Developmental Disability	Family reimbursed up to $3,000 per year	Family identifies needs in consultation with regional center worker, very flexible as to allowable costs	115 +200 get aid from special fund	$343,000.00 + $80,000 to 4 respite projects
CONNECTICUT	1) Respite	Budgeted	Mental retardation or Autism		Respite	982	$799,472.00
	2) Respite	Budgeted	Other Disabilities	30 days a year	Respite	443	$400,000.00
	3) Financial Aid	Budgeted	Family of child under 18 substantial disbility, return from or at risk of institutional placement	$2,000 per year	To cover disability related costs not covered by insurance or others	37	$74,000.00

TABLE 1: SUMMARY OF STATE FAMILY SUPPORT ACTIVITIES - 2

STATE	NATURE OF SUPPORTS	TYPE OF PROGRAM	ELIGIBILITY CRITERIA	LIMITATIONS ON BENEFITS	ALLOWABLE SERVICES	FAMILIES SERVED	CURRENT FUNDING
CONNECTICUT	4) Financial Aid	Pilot	Mental retardation or Autism (disability has major impact on home expenses, income <$58,800)	$236 per month	Cash assistance to be spent at the family's discretion	18	$50,000.00
	5) Financial Aid	Pilot	Other Disabilities (as above)	$236 per month	same as above	18	$50,000.00
DELAWARE	Respite	Mandated	Aged, disabled, mentally ill, or physically handicapped	216 hours per year Family pays up to 1/3 on a sliding scale	Respite	67	$75,000.00
FLORIDA	Services	Mandated	Developmental Disability	not specified	Arranged with case manager, have paid for therapies, supplies, equipment, medical & dental care, counseling, beh. mod. & others costs of care of person with disability	11336	$11,285,234.00
GEORGIA	Combination	Pilot	Mental Retardation Income < $30,000	$5,000 per year	Day care, counseling, diagnostic, medical & dental, clothing, nutrition, equipment homemaker, nursing, training, recreation, respite, trans. & other with approval	210	$611,562.00
HAWAII	Financial Aid	Budgeted	Developmental Disability	$2,000 per year reinbursement	Envir. modification, counseling, training, homemaker, transportation, respite, medical & other costs not covered by other source	51	$115,000.00
IDAHO	1) Respite	Budgeted	Substantial disability	18 days per quarter	Respite	182	$70,000.00
	2) Financial Aid	Budgeted	Developmental Disability Under 21 years of age Eligible for Med. Assistance significant parent involvement	$250 per month	Diagnostics, equipment, therapies, special diets, medical & dental, home health care counseling, respite, child care, clothing trans. envir. modification, & recreation	122	$50,000.00
ILLINOIS	1) Respite	Budegted	Developmental Disability	180 hours per year	Respite	3147	$4,400,000.00
	2) Combination	Pilot	Developmental Disability Income <$50,000	$3,000 per year	Case management, cash subsidy, vouchers & reinbrursement used to obtain wide range of services & supports as identifies by families	200	$320,000.00

TABLE 1: SUMMARY OF STATE FAMILY SUPPORT ACTIVITIES - 3

STATE	NATURE OF SUPPORTS	TYPE OF PROGRAM	ELIGIBILITY CRITERIA	LIMITATIONS ON BENEFITS	ALLOWABLE SERVICES	FAMILIES SERVED	CURRENT FUNDING
INDIANA	Services	Mandated	Developmental Disability	$600 per year a sliding fee scale.	Primarily respite & some traditional services provided on limited basis	600	$434,535.00
IOWA	Financial Aid	Mandated	Severely imparied as per special ed. classification Under 18 years of age income <$40,000	$246 per month	Subsidy used at family's discretion for expenses related to the special needs of the child with a disability	54	$400,000.00
KANSAS No distinct family support initatives. Some services to families provided through regional centers	Services	Budgeted	Developmental Disability	Individually determined based on need	Case management, respite, pre-school & other services	NA	NA
KENTUCKY No distinct family support initatives. Some services to families provided through regional center	Services	Budgeted	Developmental Disability	Individually determined based on need sliding fee scale	Respite and other in-home services as provide through local mental health centers.	3541 services delivered (duplicated count)	Respite: $233,074 Other services: $978,720
LOUISIANA	1) Respite	Budgeted	Physical or mental disability, risk of placement without service	720 Hrs in 6 Mos	Respite	941	$1,270,000.00
	2) Financial Aid	Budgeted	Mental Retardation	Individually determined	Reinbursement for needed goods & services-flexible determination	64	$334,378.00
	3) Financial Aid	Pilot	Under 18 years of age Severe Developmental Disability Live in pilot area	$250 per month	Individually determined by family	30	$200,000.00
	4) Planning	Mandated			New legislation to plan a comprehensive system of community & family supports		
MAINE	Respite	Budgeted	Children (<20 years) with special health needs, & 1-5 year olds with mental retardation	24 day a year	Respite	450	$1,000,000.00
	Respite	Budgeted	People with mental retardation & autism age 6-adult		Respite	1200	$500,000.00

TABLE 1: SUMMARY OF STATE FAMILY SUPPORT ACTIVITIES - 4

STATE	NATURE OF SUPPORTS	TYPE OF PROGRAM	ELIGIBILITY CRITERIA	LIMITATIONS ON BENEFITS	ALLOWABLE SERVICES	FAMILIES SERVED	CURRENT FUNDING
MARYLAND	Services	Mandated	Developmental Disability at risk of out of home placement		Respite, Beh. Mod., recreation, equipment, medical supplies, therapies This is regarded as payor of last resort	1500	$4,000,000.00
MASSACHUSETTS	1) Services	Budgeted	Person with mental retardation living with birth/adoptive family	Determined based on individual assessment	Services releted to care of family member including trans., equipment, homemaker, respite, therapies, counseling & others	3000	$3,500,000.00
	2) Respite	Mandated	Developmental Disability	100 hrs in 6 mos.	Respite	10000	$15,000,000.00
MICHIGAN	1) Financial Aid	Mandated	Child (<18) with severe disability as defined by special ed. regs in birth/adoptive home with income under $60,000	$256 per month	Used at family discretion for care of family member with a disability	3300	$9,429,251.00
	2) Services	Mandated	Developmental Disability	Determined based on individual assessment	Case management, respite, training, counseling, support groups, crisis intervention & others through community mental health center		$5,250,000.00
MINNESOTA	Financial Aid	Mandated	Person with mental retardation or related condition, < 22 yrs eligible for residential placement	$250 per month	Grants in amount of cost of services in family service plan including not limited to diagnosis, homemaker,equipment,therapies trans., pre-school, day care, & respite	400 in 46 of 87 counties	$1,128,700.00
MISSISSIPPI No distinct family support initatives. Some services to families provided through the state's pilot early intervention project.							
MISSOURI No distinct family support initatives. Some services to families provided through state's purchase of services	Respite	Mandated	Developmental Disability Means test for financial eligibilty;	21 days per year other services based on need sliding fee scale	In addition to respite, early intervention, home health care, and counseling are provided. However, not all services are available in all regions of the state.	3034 duplicated count	$3,638,053.00
MONTANA	1) Services	Budgeted	Developmental Disability Child (<18 yrs of age)		Training, equipment, evaluation, therapies, case management, support groups, & information & referral	476	$1,351,659.00

TABLE 1: SUMMARY OF STATE FAMILY SUPPORT ACTIVITIES - 5

STATE	NATURE OF SUPPORTS	TYPE OF PROGRAM	ELIGIBILITY CRITERIA	LIMITATIONS ON BENEFITS	ALLOWABLE SERVICES	FAMILIES SERVED	CURRENT FUNDING
MONTANA	2) Financial Aid	Budgeted	Developmental Disability	$350 a year for respite	A cash reinbursement program to help families cover part of the cost of respite	542	$284,632.00
	3) Services	Budgeted	Child (<22 years) with severe disabilities returning home or avoiding out-of-home placement		Including but not limited to case management, medical care, respite, day care, home modifications, therapies, homemaker, personal care, & advocacy	73	$910,912.00
NEBRASKA	Financial Aid	Mandated	Severe or Chronic disability Income below state median & 1) Family of child needing support to stay together, 2) Adult needing support to stay employed, or 3) persons needing aid to live independently	$300 per month	Home modifications, attendant care, non-medical cost of treatment, counseling, training, home health aide, homemaker, equipment, respite, trans. & others based on individual needs. Medical expenses are specifically excluded.	187	$300,000.00
NEVADA	1) Financial Aid	Budgeted	Profound retardation care at home strains family's resources	$260 a month	Use of funds at the discretion of the family, but must describe intended use of funds in application	70	$178,478.00
	2) Respite	Budgeted	Mental Retardation, sliding scale based on income (<$30,000)	Based on fee scale	Respite	220	$66,000.00
NEW HAMPSHIRE	Services	Mandated	Developmental Disability further criteria in process of development under new family support law	Determined regionally and individually	Case management, respite, early intervention are provided as independent services. The new family support law mentions, but does not limit services to information & referral, respite, home modification, equipment, training, crisis aid, & outreach.	2000	$3,712,270.00
NEW JERSEY No distinct family support initatives. Some services to families provided through state's community services	Services	Budgeted	Developmental Disability		Case management, respite & some assisted devise would be available to people living at home.	NA	$8,793,000.00 (estimated)

TABLE 1: SUMMARY OF STATE FAMILY SUPPORT ACTIVITIES - 6

STATE	NATURE OF SUPPORTS	TYPE OF PROGRAM	ELIGIBILITY CRITERIA	LIMITATIONS ON BENEFITS	ALLOWABLE SERVICES	FAMILIES SERVED	CURRENT FUNDING
NEW MEXICO	Respite	Budgeted	Developmental Disability	Time limited & usually for families in crisis	Respite	NA	$187,000.00
NEW YORK	Services	Budgeted	Developmental Disability and child <18 years	Average benefit $1,000 per year	An array of 25 services provided by 450 private programs. Core services are respite, trans., recreation, advocacy, beh. man., & financial assistance	24000	$22,500,000.00
NORTH CAROLINA No distinct family support initatives. Some services to families provided through state's general funding of support services.	Services	Budgeted	Developmental Disability	Based on need	A variety of services are offered but the most used is respite	1700 duplicated count	$812,311.00 + $175,500 for 4 federal respite demonstrations
NORTH DAKOTA	1) Respite	Budgeted	Developmental Disability	180 hrs per year Sliding fee scale	Respite	314	funding below under services
	2) Financial Aid	Mandated	Developmental Disability < 21 years & financial need	$35 per week in reinbursement	Equipment, therapies, diets, medical/dental, home health care, counseling, respite, clothing, training, child care, recreation, trans., home modifications, excess cost of health insurance or other cost of care.	198	$300,000.00
	3) Services	Budgeted	Developmental Disability adult or child & financial need	In accord with individual services plan	Respite, case management, skill training, & family training , but not equipment or home adaptations	290	$3,677,000.00
OHIO	Financial Aid	Mandated	Developmental Disability Income <$78000 per year and child <18 years	$2500 per year sliding co-pay scale	Voucher or reinbursement for respite, counseling, training, diets, equipment, or home modification	4646	$4,777,305.00
OKLAHOMA No distinct family support initatives. Some services to families provided through state's Medicaid waiver.	Services	Budgeted	Mental retardation & medicaid eligible, over 6 years of age, previously institutionalized or at risk of institutionalization	NA	Use of Medicaid waiver to provide: habilitative services, specialized foster care, assessment, & case management	350 people from Hisson class clients	NA

TABLE I: SUMMARY OF STATE FAMILY SUPPORT ACTIVITIES - 7

STATE	NATURE OF SUPPORTS	TYPE OF PROGRAM	ELIGIBILITY CRITERIA	LIMITATIONS ON BENEFITS	ALLOWABLE SERVICES	FAMILIES SERVED	CURRENT FUNDING
OREGON	Combination	Pilot	Developmental Disability	Flexible, average is $5000 per year	Equipment, clothing, trans., medical/dental, home health, attendant care, diets, home modifications, respite, training, recreation, & counseling	75-85	$443,000.00
PENNSYLVANIA	Combination	Budgeted	Mental Retardation	Individual determination	Respite, therapies, homemaker, financial assistance, home modification, training, recreation and others as needed. Availablilty varies from county to county	15000	$12,000,000.00
RHODE ISLAND	1) Financial Aid	Mandated	Developmental Disability need subsidy to stay at home 400% federal poverty level	$75 per week	As described in individiaul services plan	91	$330,000.00
	2) Respite	Budgeted	Developmental Disability	On sliding fee scale	Respite	400	$312,000.00
	3) Services	Budgeted	Developmental Disability and eligible for Medicaid waiver	Individual determination Respite: 90 hrs per 6 months	Respite, Homemaker, home health aide, assistive devices, case management, home modifications	267	$1,225,000.00
SOUTH CAROLINA	Financial Aid	Budgeted	Mental retardation or related disability with need for support beyond usual county board services and financial means test	$200 per month in 6 mos allotment	Based on individual services plan Respite, case mangement, training, therapies, evaluation, & home modification available through county boards under community service budget.	220	$220,000.00
SOUTH DAKOTA No distinct family support initatives. Some service to families provided through general funding of developmental services.							
TENNESSEE	Services	Budgeted	Mental Retardation	$3600 per year	Equipment, respite, sitter, nutrition, clothing, adapatation/modification of home/vehicle child care & other services	59	$108,000.00

TABLE 1: SUMMARY OF STATE FAMILY SUPPORT ACTIVITIES - 8

STATE	NATURE OF SUPPORTS	TYPE OF PROGRAM	ELIGIBILITY CRITERIA	LIMITATIONS ON BENEFITS	ALLOWABLE SERVICES	FAMILIES SERVED	CURRENT FUNDING
TEXAS	1) Financial Aid	Mandated	Mental retardation, mental illness, or Developmental Disability; co-payment if income above state median	$3600 per year one time $3600 grant for modifications required co-pay	Flexible use of voucher/debit card for almost all family request including health services, counseling, training, respite, attendant care, homemaker, trans. and various household expenses	1192	$4,000,000.00
	2) Financial Aid	Pilot	Developmental Disability not served by DMHMR	*	Use of voucher as above in one pilot county	45-47	$315,000.00
UTAH	Services	Budgeted	Handicapping condition & need for family supports	Individually determined average: $2000 per year	Respite, homemaker, personal care attendant, some medical, home health, nutrition, therapies, behav. man., training, counseling & others as identified	50-60	$447,100.00
VERMONT	1) Services	Budgeted	Severely emotionallly disturbed <21 years, consideration of special circumstances	Up to 3 mos average 10 hrs a week in home	Crisis intervention, skill training, counseling, & aid in accessing comunity resources	131	$2,000,000.00
	2) Respite	Budgeted	Severely emotionallly disturbed	Being determined	Respite	50-100	$200,000.00
	3) Respite	Budgeted	Mental Retardation	264 hrs per yr more time available on sliding fee scale	Families are reimbursed at rate of $3.65 an hour for respite they arrange.	400	$544,150.00
VIRGINIA	Combination	Pilot	Mental retardation or mental illness	$3600 per year	Respite, behav. man., equipment, home modifications, and others as identified	200	$350,000.00 for 2 years
WASHINGTON	Services	Mandated	Developmental Disability	Authorized on monthly basis	Respite, attendant care, therapies, equipment, home modifications & other adaptations & others as identified & approved	2500	$2,500,000.00

TABLE 1: SUMMARY OF STATE FAMILY SUPPORT ACTIVITIES - 9

STATE	NATURE OF SUPPORTS	TYPE OF PROGRAM	ELIGIBILITY CRITERIA	LIMITATIONS ON BENEFITS	ALLOWABLE SERVICES	FAMILIES SERVED	CURRENT FUNDING
WEST VIRGINIA **No distinct family support initatives. Some services to families provided through Community Behavioral Health Centers' services.**	**Services**	**Budgeted**	**Developmental Disability**	**Individually Determined**	**Therapies, respite, counseling & nutrition as provides by Community Behavioral Health Centers**	NA	NA
WISCONSIN	Combination	Mandated	Developmental Disability <21 years of age	$3000 per year per child with disability	**Home modifications, child care, counseling, nutrition & clothing, dental/medical, diagnosis/evaluation, equipment, homemaker, home health/nursing, training, recreation, respite, trans., specialized utility cost, vehicle modification and others as identified & approved**	1300	$1,971,000.00 in 47 of 72 counties
WYOMING	1) Financial Aid	Pilot	Developmental Disability 9 children currently in state training school	$350 per month 1 time home/ vehicle modification	**Monthly payment to meet individual expenses for maintaining child at home**	9	$40,000.00 (estimated)

light of the ideology and approach described in this report, they do not approach the efforts found in many other states. Therefore, in Table 1 and in most of the subsequent reporting in this section, we show Kansas, Kentucky, Mississippi, Missouri, New Jersey, North Carolina, Oklahoma, South Dakota, and West Virginia without a designated family support activity. In the state profiles, the activities enumerated by the informants in these states as family support are outlined.

Type of Program

There is wide diversity in the extent to which family supports are firmly established in each state (see Table 2 for summary of this information). Presently, only three states (Michigan, Wisconsin, & Minnesota) have relatively comprehensive family supports established by state legislation. And, in Minnesota and Wisconsin, this legislation is not fully implemented in all counties. Three additional states (New Hampshire, Louisiana, and Illinois) have new legislation which, when fully implemented, will bring them close to a comprehensive array of supports. An additional 14 states have some supports that are mandated by state family support legislation.

Eighteen states have family supports that are governed by the policy of the state department responsible for services to people with developmental disabilities and as such are budgeted for in legislative appropriations. The informants in these states spoke of these supports as being a permanent part of the department budget. However, a line item in an departmental budget is a somewhat more tenuous than a legislatively mandated program. In seven states, family supports are small scale pilots funded by the state department or the developmental disabilities council. Three other states that have either regularly budgeted or mandated services are exploring additional family supports through pilot projects.

The services that are available to families under the rubric of family support fall into four general categories.

- The oldest and most generally available family support is **respite** services. Forty six states provide for some degree of public support for respite for families of children with a developmental disability. In four states (Alabama, Delaware, New Mexico, & Vermont), the only state supported family support is respite.

- A total of 36 states fund some other **services** in addition to respite as part of their array of family supports. As we will discuss below, there is a great deal of variability in what may be defined as an appropriate family support service. In 13 states the support to families is limited to a group of designated services.

- In the last several years increasing attention has be paid to **financial assistance** as a mode for providing flexible family supports. The 25 states which offer some form of financial assistance have developed a number of strategies (see discussion below). Currently, in 8 states the only state funded family support is provided by some form of financial assistance. It should be noted that in the interviews many of these states noted that this assistance was viewed as a supplement to services typically available through their general community services.

- Finally, 17 states use some **combination** of financial assistance and services to provide support for families. In general, these two approaches are combined in one of four ways. First, they may operate as two completely independent programs. Second, the financial assistance may be used to supplement services. Third, the assistance may be specifically targeted to purchasing specific services, such as respite. Fourth, the financial assistance may be only one component of comprehensive family support and as such is used to cover expenses not covered or available through the standard array of services.

TABLE 2: OVERVIEW OF SELECTED FAMILY SUPPORT PRACTICES - 1

STATE	Legislation	Financial Assistance	Services	Fee for Services	Respite Only	Medicaid Waiver	Pilot Project	<100 families
ALABAMA				X	X		X	X
ALASKA			X	X			X	X
ARIZONA		X	X	X		X		
ARKANSAS		X					X	X
CALIFORNIA	X		X			X		
COLORADO		X				X		
CONNECTICUT		X	X			X	X	X
DELAWARE	X			X	X	X		X
FLORIDA	X		X			X		
GEORGIA			X			X	X	
HAWAII		X						X
IDAHO		X	X			X		
ILLINOIS	**	X	X			X	X	
INDIANA	X		X	X				
IOWA	X	X				X		X
KANSAS			*					
KENTUCKY			X	X				
LOUISIANA	**	X	X				X	X
MAINE	X		X					X
MARYLAND	X		X					
MASSACHUSETTS	X		X			X		
MICHIGAN	X	X	X			X		
MINNESOTA	X	X	X			X		
MISSISSIPPI			*			X	*	
MISSOURI			*	*		*		
MONTANA		X	X			X		
NEBRASKA	X	X				X		
NEVADA		X	X	X		X		X
NEW HAMPSHIRE	**	X	X			X		
NEW JERSEY			*					
NEW MEXICO					X			

TABLE 2: OVERVIEW OF SELECTED FAMILY SUPPORT PRACTICES - 2

STATE	Legislation	Financial Assistance	Services	Fee for Services	Respite Only	Medicaid Waiver	Pilot Project	<100 families
NEW YORK			X					
NORTH CAROLINA			*					
NORTH DAKOTA	X	X	X	X		X		
OHIO	X	X		X		X		
OKLAHOMA						*		
OREGON		X	X			X	X	X
PENNSYLVANIA		X	X			X		
RHODE ISLAND	X	X	X	X		X		X
SOUTH CAROLINA		X	X			X		
SOUTH DAKOTA								
TENNESSEE			X			X		X
TEXAS	X	X		X				
UTAH			X					X
VERMONT				X	X	X		
VIRGINIA		X	X				X	
WASHINGTON	X		X					
WEST VIRGINIA			*			X		
WISCONSIN	X	X	X			X		
WYOMING		X					X	X
TOTALS:	20	25	36	13	4	30	11	15

* While these states does not identify family support as a specific priority, some services are available to families.

** These states have new family support legislation that is currently being implemented.

It was necessary to make a number of judgements to determine whether a state actually had a financial assistance program. Some states list financial assistance as part of the possible array of family supports but restrict it to assistance for a few allowable expenses such as those associated with making the home accessible. When compared with other states where financial aid is used extensively to purchase essentially anything a family identifies as a need, this limited approach seems to be merely a purchase of services arrangement rather than a true financial assistance program. For this reason, states using this approach are not listed as having a financial assistance component in their family support system.

A final important component of a state's efforts in family support is the degree to which it uses options available under Medicaid to provide for care in the family home. The issue of state approaches to Medicaid policy will be addressed below. Here and in Table 2, we are only looking for an indication that the state has given some thought about the relationship between Medicaid policy and support for families by at least developing a single Medicaid waiver. An "X" in Medicaid waiver column on Table 2 indicates that the state has at least a "Katie Beckett" waiver in place. Based on our interview 30 states meet this criteria. It should be noted that in the case of Oklahoma and Missouri, the family support aspects of the waiver are secondary to a primary focus on community services for adults. Also in West Virginia and Mississippi, the options available under the Medicaid waiver are the principal family support activity in the state.

Number of families served

The limited availability of family supports in most states becomes readily apparent when the number of families actually receiving support is examined. The range of families covered in each state ranges from 9 in Wyoming to approximately 25,000 in California. As the last column in Table 2 indicates, in 15 states the major components of the family support program serve less than 100 families. Data reported by the five states with the largest family support efforts, California, New York (24,000), Pennsylvania (15,000), Florida (11,336), and Massachusetts (10,000), should be more closely examined to determine how many families are actually receiving services beyond nominal case management and maintenance on the eligibility rolls.

Eligibility criteria

Most states have adopted relatively broad eligibility criteria for their family support efforts. As can be seen in column 3 on Table 1, the principal criteria in most instances is a diagnosis of a developmental disability. A few states have adopted a program specific definition of eligibility for their family supports. These latter criteria generally appear to be efforts to avoid the restrictions inherent in categorical approaches to eligibility. For example, Louisiana's criteria include a person with a chronic physical or mental disability that is not primarily the result of the aging process, is likely to continue indefinitely, and results in limitation in three major life area as eligible for respite services. In nine instances, states have adopted more restrictive eligibility criteria by using a narrow categorical definition of developmental disability or by limiting eligibility to one or a few diagnostic categories.

The other principal strategy for controlling eligibility for family supports is to attach conditions in addition to the presence of a disability. Five states limit eligibility for some aspect of their family support effort to people with severe disabilities. To define this term, states typically highlight functional limitations in a large number of life areas or, in Michigan and Iowa, allow "severe" disability to be defined by the state's education regulations. Nine states forego the use of a categorical approach to eligibility in favor of one based on current life situation. In these latter cases the program is usually defined as intervening to alleviate a "crisis" or to prevent an out-of-the-home placement.

Although a large number of states indicate that their family support efforts are primarily targeted on families with minor children, only 12 states limit eligibility for family supports to that group. So in most cases these programs allow for what can more appropriately be termed "in-home and family supports" since their primary focus seems to be offering the supports which people, adults and children, with a disability need to live in a family situation. The definition of family used in most states is very flexible. In practice, our interviews indicate that the programs look at the quality of the relationship of the people in the household to determine whether a particular living arrangement constitutes a home and family. In Hawaii for example a family is defined as a person living with a parent (birth or adopted), sibling, spouse, son, daughter, grand parent, aunt or uncle, cousin, guardian, or a person who has become member of an immediate family through the custom of "Hanai." The major restriction imposed by the relevant laws and regulations is, in most states, the exclusion of foster homes or other situations involving paid caregivers. But even this restriction is by no means universal and several states specifically include foster homes as eligible. This difference in policy seems to be associated with the level of support in each state for foster care. States with low foster care reimbursement rates seem to look to family support funds as a way of enhancing their rate and thereby creating a form of specialized foster care for people with disabilities.

The final major factor that is considered in determining program eligibility is family income. Thirteen states, especially those that offer some kind of direct financial assistance, also have income based restrictions on eligibility. The standard used in this determination can vary from some absolute ceiling established by the law or regulations (range: an annual income of $30,000 in Georgia to $60,000 in Michigan) to a measure tied to some changing indicator, such as a percentage of the state's median income. Additionally, thirteen of the state respondents interviewed indicated that there was a fee for service attached to some or all aspects of their family support program. In most of these cases, people at the lower end of a sliding scale pay nothing for services and at the upper end the family pays a substantial portion of the cost.

Services covered/allowable expenditures

There is wide diversity in the type and range of services and supports which states include under family supports. Table 3 attempts to organize this diversity by indicating which of 38 "services" are identified by each state as part of a system of family support. Because of state differences in service definitions, many of the services listed in the first column of Table 4 reflect the inclusion of a range of closely related service categories. As noted above respite is the only service that is universally identified as a family support. The next most frequently identified supports, adaptive equipment (31 states) and family counseling (27 states), are found in roughly two thirds of the states. No other supports are identified by more than 50% of the states.

The range of identified support services available in any one state range from no identified family support program to 27 allowable services (Louisiana & Wisconsin). The last two "services" listed in column one merit some mention since they are often used to provide the flexibility that is a key characteristic of the emerging definition of family support. In the 24 states identified as using these two options the list of available services described in state law or regulations is made open-ended by being prefaced with a phrase such as the following: "Family support services shall include but not be limited to the following services." The list of mandated services is usually followed by a section that outlines a family support planning process which will allows the family to identify either "other support needs" or "other disability related expenses or services not covered by other sources" which can then be identified as part of an individual family's array of supports.

A careful examination of the services catalogued in Table 3 soon makes it clear that there are a number of very different types of service grouped under the general rubric of family support. We suggest that this diversity can be better organized by first viewing publicly subsidized family supports as made

TABLE 3: SERVICE PROVIDED OR COVERED BY STATE FAMILY SUPPORT PROGRAMS - I

Services	States: AL	AK	AZ	AR	CA	CO	CT	DE	FL	GA	HI	ID	IL
Respite	X	X	X	X	X	X	X	X	X	X	X	X	X
Adaptive Equipment			X	X	X	X			X	X	X	X	
Family Counseling					X	X			X	X	X	X	
Occupational Therapy *						X			X	X		X	
Parent Training		X	X		X	X				X	X		
Physical Therapy *						X			X	X		X	
Behavior Management *					X	X			X	X			
Case Management			X			X	X		X	X			X
Speech Therapy *						X			X	X		X	
Home Modification			X	X					X		X	X	
Voucher/Reimbursement			X	X		X					X	X	X
Transportation			X			X			X	X	X	X	
Homemaker			X		X	X				X	X		
Individual Counseling *					X				X	X			
Medical/Dental *					X				X	X	X	X	
Skill Training *		X				X			X	X			
Special Diet						X			X	X		X	
Attendant Care		X		X						X			
Evaluation/Assessment *									X	X		X	
Home Health Care			X			X				X		X	
Child Care					X	X			X			X	
Special Clothing				X		X			X	X		X	
Recreation						X				X		X	
Discretionary Cash							X						X
Family Support Groups												X	
Nursing *			X							X			
Information & Referral													
Sitter Service			X		X	X				X			
Vehicle Modification													
Advocacy					X								
Camp	X				X								
Utilities													
Chores			X										
Health Insurance													
Home Repairs			X										
Rent Assistance			X										
Disability related expenses not covered by others							X				X		
Other as identified		X		X	X	X			X	X		X	X
Total state services	2	5	14	7	13	20	4	1	18	23	10	18	5

* Indicates a traditional developmental service which is included as a family support because it can be "delivered" in the home.

TABLE 3: SERVICE PROVIDED OR COVERED BY STATE FAMILY SUPPORT PROGRAMS - 2

Services	IN	IA	KS	KY	LA	ME	MD	MA	MI	MN	MS	MO	MT
Respite	X		X	X	X	X	X	X	X	X		X	X
Adaptive Equipment	X				X		X	X	X	X		X	X
Family Counseling	X				X	X		X	X		X	X	X
Occupational Therapy *				X	X	X		X	X	X	X		X
Parent Training			X		X	X			X		X		X
Physical Therapy *				X	X	X		X	X	X	X		X
Behavior Management *	X			X	X	X	X	X	X	X	X	X	
Case Management	X		X	X	X	X			X	X	X		X
Speech Therapy *				X	X			X	X	X	X		X
Home Modification					X								X
Voucher/Reimbursement	X				X					X			X
Transportation	X				X	X	X	X		X			
Homemaker	X				X			X		X			X
Individual Counseling *					X			X	X			X	X
Medical/Dental *	X				X								X
Skill Training *	X												X
Special Diet	X				X								
Attendant Care	X			X	X			X					X
Evaluation/Assessment *					X	X			X	X	X		X
Home Health Care					X							X	
Child Care					X					X			X
Special Clothing	X				X								
Recreation					X	X		X					
Discretionary Cash		X			X				X				
Family Support Groups					X	X		X	X				X
Nursing *					X					X		X	
Information & Referral			X					X	X				X
Sitter Service									X				
Vehicle Modification					X		X						
Advocacy						X							X
Camp													
Utilities					X								
Chores													
Health Insurance													
Home Repairs													
Rent Assistance													
Disability related expenses not covered by others										X			
Other as identified	X			X					X				X
Total state services	14	1	4	8	27	12	5	14	16	14	8	7	21

TABLE 3: SERVICE PROVIDED OR COVERED BY STATE FAMILY SUPPORT PROGRAMS - 3

Services	NE	NV	NH	NJ	NM	NY	NC	ND	OH	OK	OR	PA	RI
Respite	X	X	X	X	X	X	X	X	X	X	X	X	X
Adaptive Equipment	X		X	X		X		X	X		X	X	X
Family Counseling	X					X		X	X		X		X
Occupational Therapy *			X			X		X				X	X
Parent Training	X		X			X		X	X		X	X	X
Physical Therapy *			X			X		X				X	X
Behavior Management *			X			X		X				X	
Case Management		X	X	X		X				X			X
Speech Therapy *			X			X		X				X	X
Home Modification	X		X			X		X	X		X	X	X
Voucher/Reimbursement	X		X			X		X	X		X	X	X
Transportation	X					X		X			X		
Homemaker	X							X		X		X	X
Individual Counseling *	X					X		X			X		
Medical/Dental *								X	X		X	X	X
Skill Training *	X					X		X	X	X	X		
Special Diet						X		X	X		X	X	
Attendant Care	X										X		
Evaluation/Assessment *						X				X			
Home Health Care	X							X			X		X
Child Care		X				X		X					
Special Clothing								X			X		
Recreation						X		X				X	
Discretionary Cash		X										X	
Family Support Groups						X							X
Nursing *													
Information & Referral			X			X	X						
Sitter Service												X	
Vehicle Modification											X		
Advocacy						X							
Camp													
Utilities													
Chores													
Health Insurance								X					
Home Repairs													
Rent Assistance													
Disability related expenses not covered by others													
Other as identified			X			X							X
Total state services	12	4	12	3	1	22	2	21	9	5	15	15	15

TABLE 3: SERVICE PROVIDED OR COVERED BY STATE FAMILY SUPPORT PROGRAMS - 4

Services	SC	SD	TN	TX	UT	VT	VA	WA	WV	WI	WY	Number of states allowing service
Respite	X		X	X	X	X	X	X	X	X		46
Adaptive Equipment			X	X	X		X	X		X		31
Family Counseling	X		X	X	X	X			X	X		27
Occupational Therapy *	X		X	X	X			X	X	X		24
Parent Training	X			X	X					X		24
Physical Therapy *	X		X	X	X			X	X	X		24
Behavior Management *				X	X	X	X	X		X		24
Case Management	X									X		23
Speech Therapy *	X		X	X	X			X	X	X		23
Home Modification	X		X	X			X	X		X	X	22
Voucher/Reimbursement				X			X			X		21
Transportation			X	X						X		19
Homemaker				X	X					X		18
Individual Counseling *				X	X	X			X	X		17
Medical/Dental *			X	X			X			X		17
Skill Training *	X			X	X					X		16
Special Diet			X		X				X	X		15
Attendant Care				X	X			X		X		14
Evaluation/Assessment *	X			X						X		14
Home Health Care			X	X	X					X		14
Child Care			X							X		12
Special Clothing			X	X						X		12
Recreation			X							X		11
Discretionary Cash	X										X	9
Family Support Groups	X											9
Nursing *			X	X	X					X		9
Information & Referral							X					8
Sitter Service			X									7
Vehicle Modification			X				X			X	X	7
Advocacy			X									5
Camp	X		X									4
Utilities										X		2
Chores												1
Health Insurance												1
Home Repairs												1
Rent Assistance												1
Disability related expenses not covered by others												3
Other as identified			X	X	X		X	X	X	X		22
Total state services	13	0	20	21	16	4	9	9	8	27	3	

up of three principal components: services, case management, and financial assistance. Within each of these broad categories are a number of subordinate service categories or approaches. Table 4 organizes the family support activities described in our inquiries into related categories of support.

Services

An initial problem in organizing the data collected in the interviews was the need to decide what was appropriately called a family support service. A number of states with very limited family support efforts provide extensive descriptions of their efforts in early intervention under PL 99-457. While the mandate for integration and a family centered approach in this law are completely congruent with the emerging approach to supporting families, we decided not to consider early intervention as synonymous with family support. This decision was based on the premise that access to these services are restricted to a discrete age group and have a primary focus on prevention and/or amelioration of disability rather than on long term support of the family unit. Given the significance of these activities to children and their families, they should be integrated with other state family support efforts. As is noted below, policy makers, advocates, providers, and consumers need to adopt a cross disciplinary collaborative perspective on services to families and children with disabilities.

Traditional Developmental Services. A problem similar to the one with early intervention, occurred with developmental services as family supports. At least nine of the most frequently identified services clearly fell into the category of traditional developmental services which many school-age children receive as related services through their school program or which are available through community service or a regional service center. These nine services have a distinctly different focus from the other 24 services identified as family supports. Core family supports can be characterized by their focus on supporting the family as a whole, while those listed under traditional developmental services are individually centered clinical interventions usually outlined in an individualized plan of service. They become "family supports" when a state makes provisions for them to be delivered in the home.

Core Family Supports. The supports in this category reflect the guiding values of family-focus, parent controlled, flexible, and community-based which are intrinsic in the emerging approach to supporting families. They fall into the eight distinct categories shown in Table 4.

1) **Respite and child care** is the most available support service with 46 states making some provision in this area. As with most supports there is wide variability in what is actually available to families. In some states this service may be restricted to one form of respite no more than 10 days a year. Yet other states provide for a variety respite options, child care support, and assistance in finding sitters services for both the child with the disability and children without a disability.

2) **Environmental adaptation** is provided as a family support in 32 states. This category of support ranges from states where the public sector completely covers the costs associated with making a home fully accessible and obtaining adaptive equipment to states where partial reimbursement is provided for a portion of the costs associated with these needs.

3) **Supportive services** are provided in 27 states. These supports can take multiple forms ranging from traditional individual counseling for parents to self-help groups including family support groups, sibling groups, and family counseling services.

4) **In-home assistance** is allowed, in some form, as a family support in 26 states. This mode of support provides either for outside assistance to: a) help in the care of the person with a disability, so the prime caregiver can look to the other needs of the family, or b) assistance with the typical household activities, so the family members can see to the needs of the family member with a disability.

5) **Extraordinary/ordinary needs** are covered under family support policy in 26 states. There is extreme variability here, particularly since states with cash subsidy programs or very flexible voucher programs see these needs as being covered by those funding mechanisms. Even states with less flexible approaches, however, recognize the fact that the specialized needs of a child with a disability may substantially increase the cost of rent, health insurance, utilities, food, clothing, and so forth.

6) **Training** for parents and other family members is covered as a family support in 24 states. This training can vary widely in focus from information related to disability to information related to individual advocacy and systems change.

7) **Recreation** is an allowable family support activity in 14 states. In some states this takes the form of special camps and special recreation programs but in an increasing number of states this activity assists families to gain access to the recreational resource that are typically available in their communities.

8) **Systemic assistance** is identified in 11 states as a family support service. This category includes the provision of information to families about the resources that are available to them and, in at least 5 states, direct assistance to assure that families receive all of the services to which they have a right. In several of these latter states, this advocacy activity is consciously aimed at moving other components of the service system into line with family-centered principles.

TABLE 4:

TAXONOMY OF FAMILY SUPPORT

SERVICES

CORE SERVICES:

- RESPITE & CHILD CARE
  - Respite
  - Child Care
  - Sitter Service
- ENVIRONMENTAL ADAPTATIONS
  - Adaptive Equipment
  - Home Modification
- SUPPORTIVE
  - Family Counseling
  - Family Support Groups
- TRAINING
  - Parent Training
- SYSTEMIC ASSISTANCE
  - Information & Referral
  - Advocacy
- IN-HOME ASSISTANCE
  - Homemaker
  - Attendant Care
  - Home Health Care
  - Chores
- RECREATION
  - Recreation
  - Camp
- EXTRA-ORDINARY/ ORDINARY NEEDS
  - Transportation
  - Vehicle Modification
  - Special Diet
  - Special Clothing
  - Utilities
  - Health Insurance
  - Home Repairs
  - Rent Assistance

TRADITIONAL DEVELOPMENTAL SERVICES

- Behavior Management
- Speech Therapy
- Occupational Therapy
- Physical Therapy
- Individual Counseling
- Medical/Dental
- Skill Training
- Evaluation/Assessment
- Nursing

CASE MANAGEMENT/SERVICE COORDINATION

FINANCIAL ASSISTANCE

- Discretionary cash subsidy.
- Allowances
- Vouchers
- Reimbursement
- Line of credit

In summary, 30 states provide at least one family support services in four or more of the core categories outlined above. Of these states, 20 also provide the majority of the traditional developmental services as part of their family supports. A total of 24 states provide the majority of the traditional services as in-home and family supports. Six states provide seven of the eight core supports as permanent part of their family supports. It is worth noting that of those states with no formalized family support system, Missouri allows for most of the core family supports as part of it community services. On the other hand, the state of Washington has a clear family support mandate, yet provides few of the core services and concentrates its effort on providing traditional services.

Case Management.

Case management is distinguished from all other services because of its central role as the linch pin for all other services and supports that a family may need or desire. The literature on community services in general and family support in particular consistently underscores this unique and crucial role. Our interviews confirm the importance of case management. In most of the 23 states that identified case management as one of their family supports, it is the only mandated service that all families can be sure they will receive. Unfortunately, the availability of case management as a mandated service tells us very little about the degree to which the ideal of case management is being fulfilled in a state. In general, there are two general variations that characterize very different approaches to case management.

The first variation is the traditional approach to case management. The case manager, with a large case load fulfills an assessment and referral function. He or she listens as the family outlines their needs, or they fill out an evaluation questionnaire based on their qualitative assessment. The case manager then describes what services are available, who is eligible to receive the services, and at what cost. From this array, ideally, the family can choose what they need. In actuality, they often have to accept whatever is offered. In some cases, families are put on waiting lists, referred to other agencies or simply denied services. The case manager has the job of telling the parents not only what they need, but what they can have. Families can say what they need, but are ultimately told what they can have. To many parents this is not family support or case management but management of the family by a professional.

The preferable variation is case management that makes "family support" determined and directed by the family, with the assistance of the professionals, not the other way around. The emerging role is truly one of case managers, not family managers. In this role, the professional helps the family identify the long and short term support services they need and assists them to gain access to these services. If the services do not exist, then the case manager works to find them or provides the technical assistance to generic community based agencies to create the service or augment already existing services.

Determining which approach to case management is found in a particular state goes beyond our limited inquiries. However, based on our interviews we are able to make some judgement regarding how case management is being implemented in each state. Since this is an effort that goes beyond our interview data we feel compelled to confine this evaluation to the discussion section of this report.

Financial Assistance

The third major component in the emerging system of family supports is financial assistance to families of people with disabilities. The way in which this type of support is administered can have an immense influence on other aspects of the system of supports. A few states see financial assistance as the essence of its approach to family support. As a consequence, these states impose few restrictions on the use of funds, have the expectation that families will use them to purchase whatever services and supports they need. These states are likely to have very few publicly subsidized services available. A second group of states, that are somewhat "richer" in services, provide financial assistance in the form of service vouchers, which families can then use to make purchases from the available range of services. A third approach found in some states that have an extensive array of formal services entails using financial aid to allow families to obtain supports beyond those they offer. However this approach is coupled with significant restriction on what families are allowed to purchase. The final approach to financial assistance is very open-ended, and allows families to determine their own needs. This approach is distinguished from the first approach described because it is associated with an extensive array of publicly subsidized services. Financial assistance in these latter states is seen as a way of meeting the unique needs of each family.

The five strategies for providing financial assistance as outlined in Table 4 are not necessarily mutually exclusive since several states either use or are experimenting with several of these approaches. In addition, neither of these strategies is tied to any one of the four approaches to financial assistance outlined in the previous paragraph. The first strategy, cash subsidy, is used in the nine states indicated on Table 3. The other four methods are used alone or in combination in the 21 states which Table 3 indicates use "Voucher/ Reimbursement."

1) **Discretionary cash subsidy**. This method of providing financial assistance entails providing a family with a regular payment of a set amount of cash to defray the extra cost of raising a child with a disability. Most states that have adopted this strategy provide for the family to receive a monthly payment that is roughly equivalent to that state's SSI payment for an adult with a disability. The family may be required to provide receipts to document the use of the subsidy.

2) **Allowances**. This strategy is distinct from the first because it is usually found as a flexible component of a program that concentrates on the use of vouchers or reimbursement for expenses. It also usually entails substantially less cash than a direct subsidy. For example a family may be allotted a monthly allowance to cover the cost of respite, medication, food, clothing, or transportation. Usually the families are required to provide receipts for the full amount of the allowance.

3) **Vouchers**. This method of providing financial assistance is most often used to provide and control access to specialized services such as respite. A family is allocated so much of a service through the vouchers which are then given to the provider who is paid by the state agency. In some cases, families can use their own cash to purchase services in excess of their vouchered amount, in other cases families can only obtain the amount of service for which they have vouchers. A few states have used vouchers to arrange for such things as home adaptations, medication, or food (through arrangements which parallel food stamps) with community merchants.

4) **Reimbursement**. Using this method families pay for covered goods and services. They then submit their receipts to the family support program which reimburses them for all or part of their expenditures.

5) **Line of credit**. This is a variant of the voucher system which has been tried in Texas. Families involved in the program are issued a charge card with a monthly credit limit which they can use to cover the cost of services or supports with participating providers who bill against the balance remaining in the family's account.

Limitations on benefit to individual families

An important concern to families is the extent of limitations placed on the amount of supports available to them. As the fifth column on Table 1 demonstrates, like other aspects of family support, there is a wide variability in state practice in this area. Most respite programs have a limitation imposed on the number of days available for a period of 6 months or a year. This restriction ranges from 10 to 60 days per year. An examination of the funds allocated to the 16 discrete respite programs indicates that on average a family gets about $1,000.00 worth of respite services per year. The range on this cost is from $300.00 in Nevada to $2,222.00 in Maine. These findings must be interpreted carefully since several interviewees indicated that the limited number of providers available means that families are rarely able to obtain the amount of respite to which they are "entitled" let alone exceed that allocation.

We examined 23 separate programs in the 19 states that provide some form of direct financial assistance to families. The limitations on benefits in these programs range from about $2,000.00 to $5,000.00 per year. When the number of families served by a program is compared with the funds allocated to that program the actual average benefit during the fiscal period covered in the study averages $2,838.00 with a range from almost $410.00 in Iowa to $5,556.00 in Arkansas. This wide discrepancy reflects programs that are just getting started and so are funding some families for only a fraction of the year.

In addition, our data collection on cost did not make provision to separate the overhead cost associated with a program from the direct benefits obtained by families.

Many of the states that provide a combination of services and financial assistance or only services indicate that services and limits are individually determined. In this situation the only gauge of benefits is, the admittedly rough measure of average benefits based on number of families served and program allocation. This approach is weakened by the inability to extract an overhead cost which is included in the cost of other efforts. Within these constraints, we examined the 23 service programs found in 22 states. The average family benefit under this approach is $2923.00. The range here is from $342.00 in Kentucky to $12,478.00 in Montana's specialized home care program, which provides intensive supports to birth, adoptive, and foster families.

Current funding levels

The state effort in the area of family support varies from the $37,880.00 provided by the Wyoming Developmental Disabilities Council to support a pilot project which is returning nine previous institutionalized children to their home to the $30,511,839.00 allocated by the California Legislature to provide in-home and family support through that state's system of regional centers. In the 45 states that clearly commit a portion of their budget to family supports, the average allocation is $3,826,623.00 for a national total of $172,198,035.00. When this is compared to the national budget of $11,716,825,830.00 for services for people with mental retardation and developmental disabilities (Bradoock, et al. 1990) this amounts to a commitment of approximately 1.5% of this amount to support approximately 129,777 families.

In an effort to find a measure of state family support efforts that makes some allowance for differences in population and income level across the country we settled on the state's gross personal income. Table 5 presents these data. The first column in this table indicates the state's family support ranking based on the number of dollars committed to family support (column 3) per thousand dollars of gross personal income (column 4). The result of this computation is found in column 5. As a comparison measure the figure in parenthesis next to the personal income figure indicates how each state ranks on per capita income. The average effort on family supports in the 45 states with programs of some kind is \$0.05 per thousand dollars of personal income (*SD*= \$0.078, range \$0.44 to \$0.0017).

Program Structure

In an effort to explore the degree to which ideals such as easy access, parent professional partnership, program flexibility, and a strong parent role in the planning and oversight of family support programs are being realized the informants were asked to describe how their state's family support efforts were structured. The reader is directed to the individual state descriptions that follow this section for a view of each state's approach.

TABLE 5: STATE FAMILY SUPPORT EFFORT, PER $1000 OF PERSONAL INCOME

RANK	STATE	TOTAL STATE F S EFFORT	PERSONAL INCOME IN $1,000		F S DOLLARS PER $1000 OF PERS. INCOME
1	NORTH DAKOTA	$3,977,000.00	$9,000,000	(36)	$0.4419
2	MONTANA	$2,547,203.00	$10,000,000	(42)	$0.2547
3	NEW HAMPSHIRE	$3,712,270.00	$20,000,000	(4)	$0.1856
4	MASSACHUSETTS	$18,500,000.00	$117,000,000	(3)	$0.1581
5	RHODE ISLAND	$1,867,000.00	$16,000,000	(17)	$0.1167
6	MICHIGAN	$14,679,251.00	$149,000,000	(18)	$0.0985
7	MAINE	$1,500,000.00	$17,000,000	(31)	$0.0882
8	ALASKA	$718,000.00	$10,000,000	(7)	$0.0718
9	NEW YORK	$22,500,000.00	$327,000,000	(8)	$0.0688
10	VERMONT	$544,150.00	$8,000,000	(29)	$0.0680
11	PENNSYLVANIA	$12,000,000.00	$188,000,000	(21)	$0.0638
12	CALIFORNIA	$30,511,839.00	$511,000,000	(6)	$0.0597
13	FLORIDA	$11,285,234.00	$195,000,000	(14)	$0.0579
14	NEW JERSEY *	$8,793,000.00	$163,000,000	(2)	$0.0539
15	MISSOURI *	$3,638,053.00	$77,000,000	(24)	$0.0472
16	ARIZONA	$2,349,600.00	$50,000,000	(25)	$0.0470
17	MARYLAND	$4,000,000.00	$86,000,000	(5)	$0.0465
18	LOUISIANA **	$1,804,378.00	$52,000,000	(48)	$0.0347
19	WASHINGTON	$2,500,000.00	$74,000,000	(16)	$0.0338
20	OHIO	$4,777,305.00	$162,000,000	(26)	$0.0295
21	WISCONSIN	$1,971,000.00	$73,000,000	(23)	$0.0270
22	KENTUCKY *	$1,211,814	$47,000,000	(40)	$0.0258
23	ILLINOIS **	$4,720,000.00	$197,000,000	(12)	$0.0240
24	UTAH	$447,100.00	$20,000,000	(44)	$0.0224
25	CONNECTICUT	$1,373,472.00	$71,000,000	(1)	$0.0193
26	TEXAS	$4,315,000.00	$241,000,000	(32)	$0.0179
27	MINNESOTA	$1,128,700.00	$70,000,000	(15)	$0.0161
28	NEVADA	$244,478.00	$17,000,000	(9)	$0.0144
29	ARKANSAS	$400,000.00	$28,000,000	(47)	$0.0143
30	NEBRASKA	$300,000.00	$24,000,000	(27)	$0.0125
31	NEW MEXICO	$187,000.00	$18,000,000	(43)	$0.0104
32	IDAHO	$120,000.00	$12,000,000	(45)	$0.0100
33	IOWA	$400,000.00	$41,000,000	(33)	$0.0098
34	NORTH CAROLINA *	$812,311.00	$89,000,000	(34)	$0.0091
35	OREGON **	$305,000.00	$40,000,000	(28)	$0.0076
36	DELAWARE	$75,000.00	$11,000,000	(11)	$0.0068
37	GEORGIA	$611,562.00	$92,000,000	(22)	$0.0066
38	COLORADO	$343,000.00	$53,000,000	(19)	$0.0065
39	HAWAII	$115,000.00	$18,000,000	(13)	$0.0064
40	ALABAMA **	$325,000.00	$51,000,000	(41)	$0.0064
41	WYOMING **	$37,800.00	$6,000,000	(46)	$0.0063
42	INDIANA	$434,535.00	$80,000,000	(30)	$0.0054
43	SOUTH CAROLINA	$220,000.00	$43,000,000	(37)	$0.0051
44	VIRGINIA	$175,000.00	$102,000,000	(10)	$0.0017
45	TENNESSEE	$108,000.00	$64,000,000	(35)	$0.0017
46	MISSISSIPPI		$28,000,000	(50)	$0.0000
47	WEST VIRGINIA		$21,000,000	(49)	$0.0000
48	OKLAHOMA		$42,000,000	(39)	$0.0000
49	SOUTH DAKOTA		$9,000,000	(38)	$0.0000
50	KANSAS		$39,000,000	(20)	$0.0000

* While not family support initiative a portion of these funds provides services to families.

** A portion of this state's family support effort is financed with DD council funds.

In this section we briefly summarize the eight major structural components associated with family support that were consistently described in the interviews. None of these individual components guarantees that the ideals of a parent-controlled family-centered approach will be realized. It does seem, however, that the more energy a state or region devotes to these complex issues, the higher likelihood that it will have a well articulated system of family supports.

1) **Regional control**. At least 32 states indicated that their approach to family supports placed a great deal of control at the regional or county level. In some cases this control was on the level of managing distribution of benefits or providing services; in others the regions or counties, because of their degree of fiscal and programmatic autonomy, actually defined what family support meant in their area. The positive side of this practice places control of resources closer to families. The down side of this approach is it leads to a great deal of regional variation in the benefits available to families.

2) **Central role of case management.** In at least 23 states a person called a case manager plays a central role in the system of family supports. An awareness of a need for professional expertise to assist families in obtaining benefits and services underlies this role. However, there is incredible state to state variability in how the role associated with this job title is defined. In some cases the role is only nominal, as people with massive caseloads do little more than occasionally refer families (usually those in crisis) to potential services. In other states the case manager is in a very strong position and actually determines what benefits a family needs and gets. Finally, in a small but increasing number of states, the person works in close collaboration with families as their guide through the complexities of the service system.

3) **Parent advisory boards**. Eighteen states attempt to respond to parents and family members by assuring that they have a high degree of visibility and have a voice on the advisory board that oversees state and/or local family support efforts. In some instances, these board are really only advisory in nature, although most the of informants indicated that the policy makers do listen to them. In several states these boards are more than merely advisory and are empowered to make policy for the family support program.

4) **Individualized family support planning process.** There is obviously some sort of planning process associated with every family support effort. Seventeen states pointed out that they had articulated an individualized family support planning process that every eligible family goes through before receiving benefits. Some of these processes were an extension of the Individualized Program Plan which was required for the family member with a disability. Others were, in fact, a field test of the planning process to be used in the state's implementation of PL 99-457. A number of states have developed a process which was specific to their family support effort and focuses on attempting to actualize the ideal of family control.

5) **True decision making in the hands of parents.** This policy or practice may on its face seem somehow redundant given the description of some of the emerging family-centered approaches to case management, planning, and the role of family advisory boards, but fifteen states have felt compelled to mandate this in the laws, regulations, or guidelines for their family support effort.

6) **Use of local agencies.** This approach to services is different from the regionalized approach mentioned above. This practice points more to a privatization of family support efforts, since twelve states use local private for-profit and not-for-profit agencies as their principal vehicle for managing and/or providing family supports. In a very few cases this effort has led states to expand beyond the traditional specialized services to some of the generic resources of the community as principal family support resources.

7) **An appeal process.** Five states have established a process for families to appeal any dispute they may have regarding determination of eligibility or other aspects of family support practice to a higher authority.

8) **A mechanism for quality assurance.** Only five states indicated that they have established or were planning to establish a formal mechanism to assure that services provided as family support met certain minimum standards of quality. Most states left the entire issue of quality exclusively in the hands of families with little or no recourse other than to either find a new provider or discontinue receiving a service if they felt it was of poor quality.

Implementation Issues

In an effort to highlight some of the practical matters that any state must address in developing a family support effort, the informants were asked to discuss the issues that have caused the greatest difficulty in their state. Of course, the way an issue is expressed varied greatly from state to state and some states had a long list of issues, so the reader is directed to the individual state description to get a sense of each state's situation. Nevertheless eight major issues were consistently noted by interviewees. Here we will briefly outline these recurring implementation issues.

1) **Demand versus availability.** Twenty states pointed out that family supports have been very well received and extremely successful but that the resources allocated to these programs were no where near adequate to meet the current need. In some states it was a simple matter of under-funding which was variously attributed to the competing demands of funding facilities such as group homes or institutions or to a continuing reticence on the part of the legislature to actively provide public funds for families. In several states the difference between demand and availability merely reflected the success of a pilot program which had been an effective vehicle for promoting family supports. Now families throughout the state were clamoring for what is only available to participants in the pilot.

2) **Eligibility.** This second major issue is somewhat connected to the first. In at least ten states the issue of who should be a beneficiary of a family support program was and is a problem. Specifically, many of the programs began with an orientation to either crisis intervention, avoidance of out of the home placement, or to people with the most severe disabilities. As the experience of providers and families has grown these distinctions become less and less useful. Our informants in many of these states saw a need for more expansive eligibility criteria but they also were concerned that this change be balanced against a perception on the part of some policy makers of an almost endless demand for family supports.

3) **Statewide consistency.** This issue could certainly be anticipated, since most states either have a regional system of services, depend on county agencies, or use local private providers. Ten of our state informants mentioned that there is a significant lack of uniformity in the administration and/or availability of family support in their state.

This was a major source of tension for some families. This was a particularly thorny issue in some states where family demand for more state level control placed the family support program in confrontation with the way developmental disabilities services have traditionally been delivered in the state.

4) **Developing support services.** Four states indicated that while the state was proceeding to develop a mechanism for supporting families, the infra-structure needed to make this vision a reality was not in place. Basically these states indicated that they had little in the way of community services that were not attached to a facility, either a group home or institution. So while a family might be eligible for family supports, they may not be able to find a respite provider, an in-home behavior consultant, a parent support group, or any of the other services they needed.

5) **Accessing natural supports.** Two states highlighted the problem they were confronting as they tried to actualize the ideal of using the generic resources of the community or the natural helping network of the families. Basically the people charged with this task came from a traditional background in developmental disabilities or social services and did not have a clue about how to go about realizing this goal.

6) **Developing a planning process.** In a similar vain several states pointed out that once they bought into the strong value base attached to family support they were confronted with the need to develop a planning process congruent with this perspective. This was easier said than done, since this new approach required re-thinking of the relationship between family members and professionals, and needed to give consideration to issues such as generic community resources.

7) **Staff development.** Two states specifically discussed the need to re-examine their general approach to staff development for people working within a family-centered system of supports. Numerous other states touched on this issue as they discussed the role of the case manager and highlighted how little a standard program of professional education prepared people for these new roles. In particular, they noted a need to help people understand the implications of integration and to use that as the guide in their professional practice.

8) **Interagency collaboration.** Another two states identified the need for a real focus on interagency collaboration at the state, regional, and local level as crucial to the success of a comprehensive approach to family support. As in the case of staff development numerous other states touched on this same issue when they were asked to comment on the range of family support efforts in their state. While some states seem aware of this need and do have some sort of interagency

information exchange, very few have taken even initial steps toward developing a cross agency approach to supporting families.

Medicaid policy

A major determinant of a state's overall commitment to supporting families can be seen in whether Medicaid policy has been used to finance family support. Table 2 indicates whether a state has at least one Medicaid waiver that provides some support for in-home care of children with a disability. But the presence of single waiver does not demonstrate a family focus. The focus is on the degree to which a state has taken a family support perspective on use of Medicaid. In other words, has the state used a wide range of options available under regular Medicaid and through the various waiver options to make it easier for families of people with disabilities to obtain benefits under this program. Each state description provides an overview of the state policy as it emerged from the interviews. When these descriptions are reviewed the five following policy directions emerge:

- Twenty states indicate that Medicaid is neither used to provide family support nor is this policy under review;
- In five states, currently not using Medicaid to underwrite family supports, that policy is actively under review;
- Four states indicate that they are in the initial stages of implementing new options which allow Medicaid to cover some family supports;
- Eleven states indicate that they regard Medicaid as one mechanism for supporting families and they make relatively limited use of it to support activities such as respite or case management; and
- Ten states see Medicaid a major source of supports to families and are currently making or planning to make extensive use of it to achieve that goal.

Related efforts

In an effort to gain a sense of the degree to which the state supported families beyond the mental retardation/developmental disabilities agency and the developmental disabilities council, we asked our informants to tell us about other family support efforts in their state. In general the information that emerged from this line of inquiry was of relatively limited utility. Most of the informants clearly had little knowledge of family supports in other parts of state government. Many of the responses amounted to little more than "They should be doing something in the ... department" or "I think I heard that .... had a program." The one related effort which almost all informants were able to point to was the state's early intervention program. On average our state informants were able to identify 2 related family support efforts. The range on this was from no useful information in seven states to substantial knowledge about 5 family supports efforts in Minnesota. After early intervention the most frequently identified family support initiatives were in the state's health department, specifically the Maternal and Child Health division and the services to children with disabilities under Title V. Nineteen of our informants were aware of an interest in issues related to family support in the state mental health agency. Other departments that were identified as having family support efforts were Children and Youth, Social or Human Services, and Rehabilitation. Nine states indicated that private groups in their state were the primary source of impetus for family support. As we noted earlier the findings in this area are probably more indicative of the need for increased interagency communication and collaboration on family supports than they are a measure of what is actually occurring in each state.

Lessons learned

The final two sections of findings summarize our informants' opinions of the most valuable lessons states have learned about developing support for families and what they see as future directions. Of necessity we can only present an overview of the major recurring themes that emerged in the discussion of these questions. The individual state descriptions provide a more detailed statement of how these themes were articulated by the informants and what the specific implication are in each state.

The major lessons highlighted by our informants seemed to center on issues related to the initial design and development of a family support program. In particular, they saw that:

1) There is a need to listen to parents at all stages in designing and developing family support efforts ;
2) Those involved in developing a system of family supports need to be politically realistic and savvy;
3) A number of practical issues need to be addressed including:
    - Family support efforts must remain flexibility and constantly evaluate what they are doing,
    - It is very useful to start small and gradually develop a program while demonstrating the effectiveness of family supports to policy makers,
    - Family supports need staff who are well trained in a family-centered approach to services,
    - People involved in providing family support have to learn to coordinate all the various systems which impinge on a family's life, and
    - Family support providers need to learn about the natural resources of the family and the community and how to gain access to them

4) An effort to develop a permanent system of family supports calls for a parent run grass roots political organization with specific goals such as the passage of legislation;

5) It is important for family support efforts to establish clear guidelines and principles at the beginning;

6) The focus on parent control must be firmly ingrained from the outset; and

7) Providers should not expect families to believe from the outset that family support services will actually empower them and be family-centered--they will believe it when the programs live up to their rhetoric.

Future direction

When asked to project what the future holds for family supports in their states, our informants were very positive. They all saw growth in some form or another. The growth is projected in seven areas:

1) **Family support will become the center-piece of our system of services**. In twelve states the informants saw family support as defining the future of all services for people with disabilities. They spoke of it as providing the basis for re-ordering the state budget for services or converting the old system of services to one that focuses on families and individuals.

2) **Our state will develop a system of family supports**. In all of the states that are currently without a family support effort and in one state with a very small pilot project (total 10 states), the informants indicated that efforts were underway to establish family support as something with its own unique identity.

3) **We are developing an awareness of "family support" among families, the public, and policy makers**. In nine states that currently have either a pilot or a very small program the informant saw the immediate future as entailing a public relations effort to increase awareness about this new thing called "family support."

4) **The state will expand the range of service available to families**. The informants in eight states felt that the major issue in the area of family support was the lack of sufficient services either throughout the state or in selected regions. Hence they saw the immediate future involving growth in the range of services that they called family support.

5) **We will develop the day-to day expertise needed to support families**. Five state informants expressed some variant of the position that "We've got the values, principles, and ideology. In the immediate future we have got to develop the expertise to make all of this a reality."

6) **We will make family supports a permanent part of what we do in this state.** In five of the states with pilot projects the future revolved around an effort to translate the experience of the pilot into a permanent state program.

7) **We will increase the level of family control**. Finally in three states with relatively well developed systems of supports the informants felt that their systems was overly controlled by professionals and the future would see an increase in family control.

A COMPREHENSIVE SYSTEM OF FAMILY SUPPORTS: A SEARCH FOR DEFINITION

At this admittedly early stage in their development, supports for families of people with disabilities are at a crucial juncture. Almost every state has come to the conclusion that family support is something that it should do, but what remains undecided in most states is the direction that these efforts will take. In general the efforts we found were small scale and very new. Nationally, and in most individual states, the actual fiscal commitment to family support is a minute portion of the total budget for developmental disabilities services--facility based programs continue to absorb the bulk of the resources. To this point most family support has been "sold" to policy makers based almost exclusively on a rationale of cost effectiveness. This is a crisis intervention perspective that sees the public sector providing just enough assistance to maintain the family and avoid the demand for an expensive out of the home placement. Only in the last year or two have a few states begun to confront the basic message of family support: **It is about the ultimate reconfiguration of developmental disabilities services away from facility-based models to a *true* community system**.

As we noted in the introduction, the last decade has seen most states make the decision to get out of the business of running large congregate care institutions. Our reading of the direction in family supports leads us to conclude that within the next decade each state will confront another fundamental decision about its policy direction. In its most concise form, the question confronting policy makers is "Will we continue with business as usual, placing our primary emphasis on funding programs and facilities and providing minimal support to families and adults with disabilities who live outside our facilities, or will we shift to a truly individually driven system in which we fund the unique constellation of services and supports that each person needs?"

A few states that have recently passed family support legislation have clearly set a course in the direction of this fundamental re-configuration of services. Another small core of states that have some history in providing comprehensive family support are presently grappling with the challenge of expanding their efforts to reach out to a broader range of families and the implications that this model of support has for the other components in their system of services. Some larger states with expansive community services that are configured around a system of facilities are only beginning to realize the long term implications of family support for this system and are in the process of making decisions that will determine whether family support is an adjunct to this existing system or the hallmark of a fundamental reordering. The majority of states are only starting to explore family support and the support of individuals and do not as yet fully appreciate the implications of making a full commitment to support families.

Our purpose in this report has been to assist the development of a systematic approach to family support by outlining each state's level of commitment to supporting families, the various strategies that they are using, and some of the policy and programmatic issues they are confronting. In conclusion, we would like to outline 14 principal components of comprehensive family supports as they emerged from our interviews, examination of state documents, and review of the literature. Where possible we have provided examples of how individual states have addressed a particular component. Although, we are loathe to promote "the model" for family support, we suggest that a state that attempts to address all fourteen of these components in its policy and practice will approach the ideal system. Additionally, we feel that states that address these components will be well situated to confront the challenge of a new approach to services that supports individuals and not facilities.

With the necessary proviso that these preconditions to family support are tentative and suggestive rather than empirically validated, Table 6 presents where each state stands in relationship to each of the 14 family support components. Based on out interviews and document review we have used an "X" in the table to show that a component is in place. The presence of a "?" indicates that we found some substantial evidence that the state is making an effort related to a particular component. If a component is well established but

TABLE 6: COMPONENTS OF A COMPREHENSIVE FAMILY SUPPORT SYSTEM AS FOUND IN CURRENT STATE FAMILY SUPPORT POLICY AND PRACTICE - I

STATE	Legislative Mandate	Guiding Principles	Family Focus	Parental Control	Parent Oversight	Flexible Funding	Core Services in Place	Service Brokerage	Interagency Collaboration	Inclusive Eligibility	Statewide	Medicaid Policy	Community Centered	Active Outreach
ALABAMA *								?	?					
ALASKA *			?			?		?	?				?	
ARIZONA		X	X		?		?	?			X	?	?	
ARKANSAS *			?	?		?	?							
CALIFORNIA	X	?	?				X	?	X	X	X	?		X
COLORADO	X	X	X	X		X	X	?			?	?	X	
CONNECTICUT *		?	?	?		?		?	X		?			
DELAWARE	X										X			
FLORIDA	X	X	?	?			?	X	?	X	X			X
GEORGIA *		?	?	?	?		?	?	X			?	?	
HAWAII		?	X	X		X	?	X	?				X	
IDAHO		X	?	?		X	?				X		?	
ILLINOIS *	X	?	?	?		?	?	?	X		?			
INDIANA	X		?	?			?				?		?	
IOWA	X		X	X		X					X		?	
KANSAS											X			?
KENTUCKY								?		?				
LOUISIANA	X	X	X	X	X	?	?	?			?		?	
MAINE	X	X	X	X	X		?	?	X		X		X	?
MARYLAND	X		X	X		?		X	?	?	X		X	
MASSACHUSETTS		X	X	?	?		X	?	X		X	?	?	?
MICHIGAN	X	X	X	X	X	X	?	X	X		X	?	X	X
MINNESOTA	X	X	X	X	X	X	?	X	X			X	X	X
MISSISSIPPI														
MISSOURI							?	?						
MONTANA		?	X	X		X	?	X			X	?	X	

X Indicates that a component is present. ? Indicates that there is some indication that the component is being developed. * Components found primarily in a small pilot program.

TABLE 6: COMPONENTS OF A COMPREHENSIVE FAMILY SUPPORT SYSTEM AS FOUND IN CURRENT STATE FAMILY SUPPORT POLICY AND PRACTICE - 2

STATE	Legislative Mandate	Guiding Principles	Family Focus	Parental Control	Parent Oversight	Flexible Funding	Core Services in Place	Service Brokerage	Interagency Collaboration	Inclusive Eligibility	Statewide	Medicaid Policy	Community Centered	Active Outreach
NEBRASKA	X	X	X	X		X	?	?	?				X	
NEVADA			X	X		X		X			X	?	?	
NEW HAMPSHIRE	X	X	X	X	X	X	?	X			X	?	X	
NEW JERSEY									?		X			
NEW MEXICO									?	?	?			
NEW YORK		X	?			?	X	?	?	X	?		?	X
NORTH CAROLINA									X		X			
NORTH DAKOTA	X	X	X	X		X	X	X			X	?	?	
OHIO	X		?				?	?	X		X	?	?	
OKLAHOMA														
OREGON *		?	?	?		?	?	?		?			?	
PENNSYLVANIA		X	X	X	X	?	?				?	?	?	
RHODE ISLAND	X	X	X	?		?	?	?	?	?	?	?		
SOUTH CAROLINA			X	X		X	?	?		?	X	?	X	X
SOUTH DAKOTA														
TENNESSEE			X	X		?	?	?			X			
TEXAS	X	?	X	X	?	X	?	?	X	?	X		?	
UTAH			?	?		?	?	?		X	X			
VERMONT			X						X		X	?	?	
VIRGINIA *		?	?	?		?	?	?			X		?	
WASHINGTON	X		X			?		?		?	X			
WEST VIRGINIA									X		X	?		
WISCONSIN	X	X	X	X	X	X	X	X	X			X	X	X
WYOMING														

X Indicates that a component is present. ? Indicates that there is some indication that the component is being developed. * Components found primarily in a small pilot program.

only in a small short-term pilot project, a "?" was also used in the table. Finally a blank quadrant on the matrix indicates that we found no indication that this component is actively being considered in a state.

1. Legislative Mandate. Although a number of states with extensive family support efforts do not have family support legislation, there are significant reasons for a family support law. First of all, the law firmly commits the state at all levels -- legislative, executive, and administrative -- to family support. This makes funds committed to family support a little less susceptible to the exigencies of the budgetary process. For example, we learned of one state where family support was a part of the developmental disabilities department budget. When the state was faced with a major short-fall in revenues, the developmental disabilities agency responded to the governor's mandate for budget cuts by eliminating the entire family support program. The departmental policy makers felt that continued full funding for group homes and institutions took priority over the existence of family support. In another state where legislation required certain family support services, similar cuts were more equitably distributed across all of the programs administered by the state department. A second rationale for pursuing passage of a family support law is that the legislative process provides a valuable forum for educating the entire state about issues in family support. It is probably not an accident that most of the states with progressive family support policies have been through the legislative process. This has provided the public in general, the legislature, and the executive with an understanding of family support which would not have been possible without a public hearing of the issues. It is also noteworthy that the legislative process assures that parents will be intimately involved in the design of the support system.

- During a period of fiscal "belt-tightening" Michigan, recognized as a national leader in family supports, passed its family support subsidy act in 1983 because of extensive effort by parents and advocacy groups from throughout the state.
- The state of Louisiana is currently planning its system of family support under the direction of a legislatively mandated committee with extensive representation from the parent coalition which was instrumental in bringing this issue to the attention of the legislature.
- An effort to pass family support legislation in New Hampshire led to a law that established family controlled regional family support councils to oversee services in that state.

2. Guiding Principles. From literally every informant we heard "families are the key" and "we support families." Yet often there seemed to be a lack of clarity on the ramifications of these statements. In those interviews in states that lacked a clear set of guiding principles, the informants could indicate the services that defined family support but their definition did not go beyond the list of services. It is little wonder then that they reported that families complain about variations from program to program, department to department, agency to agency, and county to county. In states with a clear set of guiding principles our informants were able to more clearly articulate what supporting families meant in that state. Certainly, a degree of variability is one of the necessary characteristics of any viable system of services. However there is a clear need for some guiding principles articulated at the state level to assure that the services and supports available to families have a consistent focus. There are several different ways that states have articulated these statements of principle:

- In 1987 Nebraska passed a *Family Policy Act* which was modeled on some of the statements of family support principles that have been developed by various advocacy organizations. This act provides clear guidance to all aspects of state government regarding how they should relate to families and children.
- The Maine Bureau of Children with Special Needs and the Arizona Division of Developmental Disabilities have adopted official statements of policy to govern the way those agencies provide service to children and families.

3. Family Focus. The most obvious significance of "family-focused" supports is that the person with the disability is not seen in isolation but as part of the family unit. Therefore services and other supports are available to parents and siblings and not just to the person with a disability. Yet as we reflected on the meaning of this term, a second important connotation became apparent: Family-focused supports are provided in a manner that ***minimizes the cost to the family of seeking and acquiring the help they need.*** By "cost" we are not just thinking of money. Costs can be include emotional turmoil or heartache, or the personal time of a family member. If family members believe that the cost they must pay to gain entry to or be involved with a program is too high, they may well choose not to participate.

For instance, program application forms that question whether the family wants to place their child out-of-home can take an emotional toll--especially if the family's eligibility is tied to the response. In some states families are required to indicate on the family support program application that without service they would place their child out-of-home! This is a terrible and needless position in which to place families. Faced with limited funds, state officials may view such a question as a simple way to direct resources to those most in need. Yet to many, having to place in writing -- on some official looking form --

that they plan to seek an out-of-home placement for their child can be quite intimidating. And it may be too high an emotional price to pay. As one father exclaimed: "If we have to grovel for it, we don't want it."

Another example concerns the personal time of family members. Many family members hold down regular jobs or otherwise have a busy daytime schedule. As a result, program staff are most successful when they can meet with families primarily *at the family's convenience.* Program practices that routinely expect family members to take time from work or other daily demands are not favorably viewed by families. Where the cost in personal time is considered too high, families may even walk away from the program.

- The most notable strategy for "detoxifying" the application process is the entitlement model used in the Michigan Subsidy program: If the family meets certain clear cut criteria they receive the aid with no additional paper work or need for constant reviews.
- Most states and regions that are committed to the principle of a family-centered service system have learned that this ideal has many ramifications ranging from groups for siblings to parent-to-parent self help phone networks.

4. Parental Control. In the most progressive family support programs more than lip-service is given to this idea. The professional role is seem as supportive, the parents are the ones who are in charge. Regardless of the array of services on the official list, the attitude towards families in these systems is "You tell us what you need and we'll try to get it for you." Admittedly their are certain limitations imposed by some regulatory and fiscal constraints, yet in talking to people working in these localities we really got a sense that they saw themselves stretching these limits to the extreme for families. It is noteworthy that they made every effort to design their services to let families *know* that they, the parents, are in charge.

- Some service agencies recruit "experienced" parents to play a formal role in the delivery of services. For example, in Calvert County, Maryland, family support services to an individual family are coordinated by a parent counselor who is also the parent of a child with a disability and works as a counselor for the project.
- Minnesota is exploring a mechanism to allow parents to actually chair the meetings of the interdisciplinary team that determines the service plan for the family member with a disability.

5. Parent Oversight. Many current organizations have parent and consumer representation on boards. In the area of family support, we feel that substantially more is needed. All organizations that engage in family support should be *directed* by boards that are run by parents who represent the full range of people served by the program. This perspective suggests a system in which a parent board sets policy at the state level which is implemented under the guidance of county or local level family boards that oversee the activities of direct service providers that are in turn also required to have parent boards. Clearly at the state and county level these parent boards should be reimbursed for their time and expenses.

- The new family support legislations New Hampshire provides for parent controlled advisory boards to coordinate family support efforts throughout the state.
- In Michigan parents are actively involved on policy boards at the state and county level and as monitors involved in quality assurance activities.

6. Flexible Funding. All of the talk of parent control and family-centered services is meaningless if the state does not have a mechanism in place to meet the unique needs identified by families. There is a growing awareness that any family support effort should not be restricted to a narrowly defined array of services. Just because a particular service is not used very often does not mean that it should be eliminated from the family support options. On the contrary, such rarely requested supports are likely to be particularly crucial to the small number of families who need them. Based on this premise, any comprehensive family support effort has to include some way of meeting the truly individualized needs of a family. One major strategy for providing this flexibility has financial assistance outlined above. The principles of parent control and family-centered dictate that the most effective strategies are the ones that put the fewest strings on the use of flexible funding mechanisms.

- The use of a discretionary cash subsidy in states like Michigan and Iowa provides the least incumbered approach to providing financial assistance to families.
- A number of other states such as Wisconsin, Minnesota, and Texas have been able to develop alternative approaches to flexible funding that also minimize the "cost" of support to families.

7. Core Services. While the ability to respond to unique needs with strategies such as a discretionary cash subsidy are a crucial part of a systematic approach to family support, just giving a families cash may not meet all of their needs. Many families of people with disabilities have specialized needs which cannot be addressed by the generic services currently available in their communities. They will continue to have a need for trained respite providers to care for children with complex medical needs or significant behavior difficulties. They will need access to information and referral to specialized developmental services and to parent support groups. If these and other core services are not available, cash subsidies will not make them magically appear.

In this regard, it is important to note that a comprehensive system must balance the provision of core support services, cash coordination activities, access to specialized developmental services, and flexible funding mechanisms if it is to truly be supportive of families.

- **Michigan's use of a dual system of family supports with a cash assistance component administered at the state level and services provided at the local level by community boards provides one approach to balancing these multiple needs.**
- **Most of the states that have adopted family support legislation have made sure that the law mandates some specific services as part of family support, but have almost invariably included language asserting that the true measure of need should come from the family. Hence the list is not meant to be exhaustive.**

8. Service Brokerage. In a family-centered system of services, the parents truly are the ultimate case managers for their children. Nonetheless the complex challenges offered by any disability means that the family need the support of responsive professionals. The professional who fills the case coordination role needs to have a thorough knowledge of the system of services available to the child and family. This knowledge must then be provided to families in a manner that offers them alternatives and support when they select a particular option. This role in many ways is the key to any system that enables and empowers parents while acting as a prod to move the service system in the direction desired by people with disabilities and their families. In developing their family support programs, several states make available to families this type of "consultant."

- **In Wisconsin, the family support coordinator or case manager acts as a kind of service broker assisting the family through the bureaucratic maze of available programs and services. The worker can also act as an advocate in helping the family to make maximum use of community services, such as community recreation programs, medical and dental services, public transportation, and other generic service providers.**

- Montana is developing a family trainer model of service coordination that seems especially well adapted for a thinly populated "service-poor" state.

9. **Interagency Collaboration.** Many families have needs that cut across more than one government agency. For instance, families who qualify for family support, administered through a department of developmental disabilities, will also interact with their local school district. Other families may also qualify for any of several government benefits programs, such as food stamps or AFDC. Still others will be receiving services under Medicaid. Taken together, families are often challenged to negotiate multiple agencies at once--often a frustrating task and made more so when the policies of one agency seem to conflict with those of another.

Family support systems have their greatest chance for success when state agency officials work together. Families should not have to cope separately with each part of the state system. As the state moves to develop a comprehensive family support program, officials should take time to understand how existing policies may or may not be working well on behalf of families. Special care should be taken to identify any instances where the policies of one state agency seem to conflict with those of another. With this information in hand, policy makers and family members can work together toward building a more responsive system of supports by developing cooperative agreements among agencies that truly work for families.

- In Ohio, legislation has established the interdepartmental cluster for youth which requires that representatives of all states departments concerned with children's issues meet at the state and local level to insure that no child's needs are lost in a shuffle over agency responsibility.

- In Maine the Bureau for Children with SpeciaL Needs was established to assure that one public agency developed a compehensive vision of the issues confronted by children with disabilities and their families. To assure that its goals are achieved it works in close collaboration with the Interdepartmental Council on Child and Family Policy.

10. Inclusive Eligibility. Eligibility for family supports should not create competition between families of children with varied needs over scarce public resources. Any mechanism that sets up such competition must be viewed as a cynical and divisive effort to control families rather than support them. Parents know that resources are limited and are fully supportive of efforts to devise some equitable system for distribution. It is crucial that parents and advocates have direct involvement in efforts to set these policies with a focus on assuring that families receive the assistance **they need** regardless of diagnostic category, level of disability, or family income.

A major limitation to the current approach to family support in many states is the use of a narrowly focused categorical definition of eligibility which requires a specific diagnosis to obtain services. This approach fails to take into account that the presence of a particular diagnosis often tells very little about the needs of a person and his or her family. It also ignores the fact that people with very different diagnoses can place very similar demands family members. Some states have attempted to address this limitation by having broad eligibility based on diagnosis but restricting certain supports (such as direct cash) to people with the most severe disabilities. In reality this restriction can be just as limiting as use of narrow categorical criteria. It fails to take into account that the unique constellation of individual and family characteristics can place a family of a child with a "mild disability" at greater risk than another family with a child who has a very severe disability.

Most family support programs, and especially those with a significant financial assistance component, have some restriction on eligibility based on income. Taken alone, an income based criteria can be misleading. For example, while a family may earn well over $60,000 per year, if their child has exceptional medical expenses or a need for expensive adaptive equipment these earnings may be severely depleted. Care must also be taken to assure that income eligibility criteria, not be set too low. In Michigan, for example, the income level is set at $60,000 of taxable income. However, in another state, with a similar family assistance law the income cut-off is $40,000. Many single income families have little trouble meeting this criteria. But the added income of a cash stipend may make it possible in some families for a second parent to return to work, given that the stipend could be used to pay for needed day care. This outcome may be highly beneficial to the entire family. However, the money resulting from the second income could well make the family ineligible for continued cash assistance. This type of "Catch 22" trap will not be acceptable to many.

- Texas has created multiple family support programs in an effort to assure that no one in need of family supports falls through any cracks in the eligibility criteria.
- Utah has adopted a somewhat more functional definition of family support eligibility by saying supports are available to the family of a person with a handicapping condition who is in need of family supports. In this case, need is defined in terms of risk of out of home placement.

11. Statewide. A system of family supports cannot be truly comprehensive if it is limited to a small pilot project, is unavailable in some regions of a state, or is administered very differently in each county. Though some states can point to a few fairly comprehensive efforts, the ideal of an equitable statewide system has not yet been fully realized. Several states are attempting to balance the competing demands of regional control and statewide access to supports.

- Washington has adopted state regulations which mandate equal access to family support throughout the state.
- In an effort to maintain regional autonomy with all its strength some states, like Nebraska, have decided to manage only certain specialized components of their family support system at the state level.

12. Medicaid Policy. As we pointed out above, since Medicaid is the principle federally funding mechanism for people with disabilities, the options selected in any state can have a major influence on the level of support available to families. In most states, family supports that are covered by Medicaid are not the result of a conscious policy decision but are the secondary outcome of a general community service waivers. Yet the experience of states that have consciously developed Medicaid policy with a family support focus demonstrates the benefits.

- Minnesota has adopted some of the broadest eligibility criteria to make Medicaid available to children with disabilities and has developed four Medicaid community waivers to provide for in-home and family supports.
- West Virginia has developed a community-based waiver that provides for parents to be reimbursed for certain components of their child active treatment plan which are implemented in the home.

13. Community Centered. As we noted earlier, there is a great deal of rhetoric in the family support movement about how the formal service system should nurture informal supports and generic community services related to the support of families. Two premises underlie the emphasis on "natural resources." First, it is assumed that the resources of the formal support system are too limited to meet the full range of family need. Second, it runs counter to the value of community integration to make a person or a family exclusively dependent on specialized services since this ultimately cuts the service recipients off from their neighbors. Yet, in reality this ideal is only now being systematically explored. An increasing number of state and local programs are actively attempting to encourage a sense of community and mutual aid in support of families.

- In North Carolina, Project SHARE was developed to promote supportive exchanges among people within a bartering framework. Participants included both caregiving families and others without persons at home with disabilities. Participants list items they are willing to exchange for needed supports or services. Using the list, people call one another and independently arrange exchanges.
- In Little Rock, Arkansas, Project KIDS has focused on developing and operating means for providing integrated preschool services for children with developmental disabilities, birth through five years old. The project provides placement into cooperating day care centers and offers on-going technical assistance to these center staff.
- In St. Louis, Missouri, the YMCA, the largest day care provider in the city, is offering integrated day care at all its sites for children with disabilities. These children are served right along with their non-disabled peers.
- In Maine, a joint effort involving various public sector agencies and the American Red Cross has succeeded in producing a training curriculum to prepare persons for providing respite care. Local Red Cross chapters thorouhgout the state are now providing this training as part of their usual group of health and safety courses.

14. Active Outreach. A family support effort does little good for families if they never hear about it. Therefore it is crucial that initially any new program be accompanied by an extensive campaign to let families know about family support and see it as something they can use. Subsequently information should continue to be actively disseminated through all agencies and services which are likely to encounter parents of a child with a disability. From the interviews it seems that many states have seen this effort at "getting the word out" as secondary to the primary work of dispensing financial assistance or services. In fact, if a services system is truly family-centered getting basic information to families is a central activity.

- **Minnesota and Florida both make extensive use of the full range of public and private social services agencies so that all eligible families will be aware of the state families support program.**

In conclusion, a final point needs to be made regarding this and any subsequent efforts to describe state family support practices. There are likely to be significant differences between the ideal of family support as it emerges from interviews with policy makers and providers or review of state legislation, regulations, or other documents and the reality of families' experience. As an example, we can consider respite nominally the most readily available family support. Based on the figures presented in this report it would seem that most families that have a child with a developmental disability should be able to obtain some level of publicly supported respite. However, a recent survey of parent's experience with respite (Knoll & Bedford, 1989) found that although respite appears to be widely available in many cases this service is not truly accessible to families. This suggests that any future efforts to assess state efforts in the area of families supports should supplement any survey of administrators and policy makers with an evaluation by consumers in an effort to determine the degree to which the ideals of family support are truly being realized.

PROFILE OF STATE FAMILY SUPPORT PROGRAMS

ALABAMA

Name of Program: None specified

Nature of program: Pilots, for respite and general department services.

Date of Implementation: Exact date uncertain but at least 5 years ago.

Administering Agency/Contact Person: State of Alabama Developmental Disabilities Council Contact: Joan Hannah, Ed.D., Director, P.O. Box 3710, Montgomery, AL 36193-5001

Type of Program: Respite

Number of Families Served: 65 people are served with in-home respite under the pilots, and as many as 378 are served in a segregated camp/respite experience.

Eligibility Criteria: There is no income eligibility but individuals using respite service must have a doctors certificate indicating they have a developmental disability. Respite is used primarily with adults, who in some cases may contribute some funds for the service. The focus of the pilot programs is mainly those individuals labeled as having severe disabilities.

Services Covered/Allowable Expenditures: Respite services including supervision, personal care, training and companion aide services to children and adults.

Limit on Benefits to Individual Family: 10 days of respite annually and 20 in some areas.

Current Funding Level: $325,000 (Developmental Disabilities Council budget)

Background: The pilot respite programs funded by the Developmental Disabilities Council began approximately 5 years ago. Though the Council provides the funds, the programs are administered by the Department of Mental Health and Mental Retardation (DMHMR).

The State of Alabama is broken up into 5 regional catchment areas. The goal of the Council has been to develop respite services in one area and use their program to get the program well established in that region before moving to another area. The Council is presently involved in 3 of the regions and financially is still totally responsible for the funding. There are other respite programs existing in the state are sponsored by United Cerebral Palsy and the Association of Retarded Citizens.

Program Structure: The State of Alabama has very few supports that can be designated as family supports. Services that might assist families are not confined to one program or even agency as noted above. Respite efforts come from a variety of different sources.

Under the Department of Mental Retardation, there are several programs listed that might assist in supporting families. These include services to enhance specific skills of the family unit including family skills/training, medical monitoring and general health training, such as personal hygiene and medication monitoring training. Case management offers specialized testing services, referral and counseling. Case management services are included in every service provided, but there has not been coordination across services so an individual or family may have as many as five or more case managers depending on the number of different services they receive. A new program is designated to begin in October of 1989 with a small group of individuals where one case manager will coordinate all service needs.

Services are provided through regional community service centers. Families must apply through the regional office or in the case of the respite pilots they may apply through the Developmental Disabilities Council. They are then referred to a caseworker who contacts them and assists them through the evaluation process. Needs are determined through the case manager and the regional service office. They in turn take care of the financial aspects and parents receive no direct funding.

Parents have little direct control of the service they receive but have on occasion asked for a person known to them to provide respite. Such a person must go through an in-service and certification process, if the child or adult is going into that person's home. Programs are monitored through Department of Mental Health and Mental Retardation standards. There is both internal and external monitoring. Families are able to request evaluation of the respite services.

Recently a survey was conducted of 308 families regarding their ability to get necessary services. The overriding finding was that families are unable to obtain enough services, and some receive none at all. Those receiving respite services were satisfied with them but that opportunity is available to a very few families.

Implementation Issues: Limitations in services have created a demand much greater than what can be provided. It is difficult to determine how many individuals are waiting for services, but waiting lists exist for almost all services. There are specific groups of people that receive few services, especially related to respite (those labelled severely sensory impaired, and those having traumatic head injury).

There is liitle efforts at interagency cooperation other basis then the very limited efforts beginning in the area of early childhood.

Medicaid Policy: The state is negotiating and in the process of applying for several waivers. It has been difficult for agencies to pool their resources and come up with the state match for federal dollars. There is presently a commitment from the Governor related to these efforts. For further information contact: Ray Owen, Division of Mental Retardation, 205-271-9290.

Related Efforts

Department of Education. (This Department is the umbrella for Special Education and Crippled Childrens Services) Efforts related to P.L. 99-457 take place under this department which has also given rise to interagency planning efforts and more extensive parental involvement.

Early Intervention and Infant Stimulation. Contact: Chris Kendall, 205-281-8780.

Special Education. Contact: Ann Ramsey or Julia Causey, 205-242-5099.

Crippled Childrens Services. (Efforts related to Interagency Coordination Council for P.L. 99-457) Contact: La Mona Lucas, 205-281-8780.

Department of Health. Home health care, visiting nurses and clinics are offered through the health department. Contact: Dr. Earl Fox, State Health Officer, 205-261-5052.

Evaluation: Services in the State of Alabama, though beginning with early intervention, and running throughout the life cycle, appear to be limited. Although human service agencies offer some family support services, there is a need for a broader focus that would include all people with disabilities. The state is not committed to looking at the needs of families per se and support for such projects have been very limited. Those offered are funded by outside sources for the most part (respite). There is little focus on children's needs and a large portion of funds in the state goes to supporting institutions.

Though there are attempts, (Developmental Disabilities Council specifically) to look at ways to provide families with more involvement and flexibility in choosing and receiving services this effort appears very limited, and there do not seem to be strong efforts to move in this direction.

Models derived from looking at efforts in other states would be a good place to start in choosing future directions. Such a process in combinations with current efforts to empower and involve parents in services could be a powerful resource.

Future Directions: Family Support is a growing issue in the state. There will be efforts to:

- Apply again for a family support grant in order to train and empower families.
- Develop a more adequate case management system.
- Conduct statewide advocacy training using groups that already exist in the state. There are efforts along these lines that will begin in September of 1989.
- Possibly initiate a cash subsidy program, drawing from models developed in other states.
- Change the role of the state Developmental Disabilities Council to one that works collaboratively to *develop* service rather than to *provide* service.
- Encourage efforts started by one parent in the state, Friends for Life group in which parents are offering support to each other. This began as part of a church group and continues with no funding.
- Increase efforts related to advocacy and public education aimed at parents, professionals, lawmakers, and the general public regarding the needs of families are important future efforts.

Lessons Learned: It would be beneficial to look nationally at efforts occurring not only in the area of Family Supports but in other service areas as well.

Materials Reviewed

Alabama Developmental Disabilities Planning Council, Annual Report, Fiscal Year 1988.

Alabama Developmental Disabilities Council, Proposal to Humans Services Research Institute and its subcontractors United Cerebral Palsy Associations, National conference of State Legislators. 7/89.

Alabama Mental Health/Mental Retardation Services Systems Plan, Alabama Department of Mental Health and Mental Retardation, 1984-1989.

Department of Mental Health and Mental Retardation, 1987-88 Annual Report.

Directory of Alabama Developmental Disabilities and Mental Retardation Service Programs, Alabama Developmental Disabilities Planning Council, Alabama Department of Mental Health and Mental Retardation, 1989-1990.

Minimum Standards For Community Programs Serving Mentally Retarded and Developmentally Disabled Persons, Division of Mental Retardation, Revised 1988.

Preliminary Findings and Recommendations of the Alabama Disabled Persons Protection Commission, March 30, 1989. Don Siegelman, Attorney General, Chairman.

Parents-Partners in Special Education, Bulletin 1988, No. 64.

Status Report: Early Intervention Programs 1987-1988, Interagency Coordinating Council, bulletin No. 79, 1989.

ALASKA

Name of Program: Individual Assistance

Nature of program: Budgeted Pilot

Date of Implementation: NA

Administering Agency/Contact Person: Division of Mental Health and Developmental Disabilities, Contact: Mike Renfrow, Developmental Disabilities Program Administrator, 907-465-3370

Type of Program: Services

Number of Families Served: Probably fewer than 30 receive intensive services but a total of about 436 receive respite and in-home training.

Eligibility Criteria: There are no age criteria. The person must meet the categorical definition of developmentally disabled which includes CP, epilepsy, and autism. There are no income eligibility criteria, but there is some payment by family for respite services based on sliding fee scale.

Services Covered/Allowable Expenditures: Services received can include almost anything but specifically include: respite, specialized training for family (i.e., sign language classes), attendant care, in-home training. Services thus far have been provided only when a family is in crisis. There are no guidelines for what can or cannot be received.

Limit on Benefits To Individual Family:

Current Funding Level: approximately $718,000

Background: The State of Alaska has not yet developed a family support program but has begun working in the past few years toward establishing such a program. The money presently allocated for supportive programs is through the Mental Health/Developmental Disabilities Division (MH/DD). Funding is presently available statewide but has been used predominantly in small communities where access to services are more limited. Money is frequently used in crisis situations.

Program Structure: There are as yet no stated goals, because Individual Assistance is not yet a "program." When a family makes a request for services, which is often a request for respite care, service eligibility is determined as well as what services are in fact available. In some cases, the service may be offered outside the community, although this is viewed as undesirable.

Once eligibility and available services are determined, the priority for services is determined by whether or not the family is in or has gone through a crisis.

A pilot case management program has just begun on a very small scale. Presently no organized system of case management exists. Neither is there active outreach, which could enable families to find out about available supports. A Regional Program Specialist has just been hired to try to lay the groundwork for programming, which would reach more families.

Alaska has several parent advocacy groups, Association for Retarded Citizens parent groups and parents on the Developmental Disabilities Council. Parents have not focused on family supports as an issue, but the topic appears to be gaining interest.

There is currently very little quality control. DMH/DD is drafting regulations which will be the basis for program and fiscal monitoring.

Implementation Issues: Eligibility is open to all age levels with a categorical definition of developmental disability. There is not a fee. Some families pay on a sliding fee scale for respite services, at the discretion of local programs.

There are currently 400-500 families on a waiting list for support services in the State of Alaska, a figure which does indicate what the need might be in the more remote and rural areas of the state.

The state has an Interagency Coordinating Council that was established around P.L. 99-457, which is promoting opportunities for collaborative discussion and planning.

Because of the geographical distances that exist in the state, DMH/DD emphasizes the need to develop supports which build on community resources.

Medicaid Policy: The state has taken a restrictive view of waiver usage, and is without a Medicaid waiver. There is some personal care attendant funding offered through Medicaid but it is very limited in terms of the number of hours.

Related Efforts

Education. The 0-3 age group is receiving a lot of attention and looking at issues related to family supports. Deborah Veit, Infant Learning Coordinator, 907-277-1651.

Special Education. A transportation project working on trying to keep children in home communities as they transition out of school is a federally-funded pilot being done in one community through Special Education Services agency. For more information, Roy Anderson, 907-279-9675.

Department of Mental Health. A program developed to bring children who were in out-of-state placements back to Alaska is an initiative through the Department of Mental Health and some interagency efforts. John Vandenberg, 907-465-3370.

Health Department. Alaska has a well-developed system of public health nurses that do home visits to families with newborns. Elfrida Nord, 907-465-3150.

Division of Mental Health and Developmental Disabilities. A program for medically fragile and technologically dependent children, assists families in getting needed services. Kaleen Lowe, 907-561-4247.

Evaluation: The issue of family supports in the State of Alaska appears to be an issue gaining popularity at all levels and there is speculation that within five years, a more defined family support program will be the basis of the support system in the state. Alaska seems to be on the threshold of more clearly defining their philosophy and direction related to family supports.

Presently, there seem to be scattered efforts in supporting families beyond those that are already provided in crisis situations. There is a great deal of uncertainty as to who will receive what services and for how long. Families receiving services expect that services will be provided for a short time and then cut. Given that so little is available in formal services, an opportunity exists to avoid building an elaborate service system and instead go with family supports. With all the rural areas in the state the idea of building on local resources is compatible with a localized model of family support.

Future Directions: There needs to be an increase in public awareness and support from parent groups around the issue of family supports, in order to deal with likely resistance to the change from the current reliance on children's group homes. Long-term goals in Alaska appear to be moving toward a cash subsidy system in which gatekeepers find needed services and the state provides resources. The movement is being directed away from facility-based programming toward a strong focus on local needs and resources.

Lessons Learned: From the limited number of families that have been served, it is obvious that they are happy with what they have received, which has created even more momentum in that direction.

ARIZONA

Name of Programs: 1) Assistance to Families
2) Respite and Sitter Services

Nature of Programs: Budgeted

Date of Implementation: Assistance to Families, July 1986

Administering Agency/Contact Person: Alice Prather, Division of Developmental Disabilities, P.O. Box 6123, Site Code 719A, Phoenix, AZ 85005, (602) 258-0419.

Types of Programs: 1) Assistance to Families allows direct payments to families for services or goods that assist them in maintaining a family member with disabilities at home. 2) Respite and Sitter Services reimburses families for temporary in- or out-of-home care.

Number of Families Served: 1) Assistance to Families - this program has assisted 177 families since its inception in 1986. 2) Respite Care - 2,153.

Eligibility Criteria: Assistance to Families and Respite Care both are open to families caring for a family member with a developmental disability.

Services Covered/Allowable Expenditures: 1) Assistance to Families: payments for services and resources must be authorized by the Individual Program Planning team or the Services Review Committee, and the appropriate District Program Manager for the Division of Developmental Disabilities. The Division will only approve those services that can be purchased at a reasonable cost and meet the goals of the program. Services that may be purchased under the Assistance to Families program include, but are not limited to homemaker, home health aide, personal care, shelter co-payment, transportation, chore maintenance, home management training, home adaptation, repair, renovation, visiting nurse, and adaptive equipment. 2) Respite and Sitter Services: respite care is intermittent short-term overnight care, sitter service is intermittent short-term care not involving overnight care. Both types of care can be provided either in or out of the family's home.

Limit on Benefits to Individual Families: 1) Assistance to Families allows a maximum of $400 per month or $4,800 per year is available to purchase services which may be an ongoing, time limited, or onetime purchase. Families are required to assist in a financial co-payment for services. Families must show receipts for services. Co-payment may be waived, if this occurs families will still be required to document in-kind contributions (such a contribution could be volunteer time). 2) Respite Care and Sitter Services requires families to participate in a co-payment of these services.

Current Funding Level: 1) Assistance to Families: Information requested, but never received. 2) Respite Care and Sitter Services -- $1.5 million.

Background: In the spring of 1989, the Division of Developmental Disabilities adopted a statement in support of families. This three page document sets down in writing a philosophy for providing services to persons with disabilities and their families. The state office has requested that this document be incorporated into the statewide Child Welfare Core Training for new case managers and has encouraged each regional office to include it as part of their new employee orientation. This is one small indication of the growing importance of family support in Arizona's service system.

In Arizona developmental disability is defined as a severe chronic disability which is a) attributable to mental retardation, cerebral palsy, epilepsy, or autism; b) is manifest before the age of 18; c) is likely to continue indefinitely; d) results in substantial functional limitations in three or more of the following areas 1) self care, 2) receptive and expressive language, 3) learning, 4) mobility, 5) self-direction, 6) capacity for independent living, and 7) economic self-sufficiency; and e) reflects the need for a combination and sequence of individually planned or coordinated special, interdisciplinary or generic care, treatment, or other services which are of lifelong or extended duration.

Program Structure: The Arizona Division of Developmental Disabilities is a division of the Arizona Department of Economic Security and operates services out of six regional offices. Each region has advisory councils composed primarily of parents. The councils assist the regional offices in an annual planning effort. Delegates from each region attend a state planning conference to share information about local concerns and needs with the Division of Developmental Disabilities.

1) Assistance to Families. This program provides direct payments to families on the behalf of a child or adult with developmental disabilities. The purpose of the program is to support families in their efforts to keep their family member with disabilities in the family home or to help maintain an adult family member in an independent or semi-independent living situation. While the program provides direct payments for services, only authorized services may be purchased. Families must participate in co-payment of these services (see Services Covered section, page 1). To receive support from this program families must apply at their regional office and work with a case manager to complete an application. Families denied services may request a Programmatic Administrative Review, which is the formal appeals process for all state services.

2) Respite and Sitter Services. Families in need of respite or sitter services should contact the Respite/Sitter Coordinator in their district. The Coordinator will provide the family with a list of certified providers in their geographic area. Prior to using respite or sitter services the family's co-payment for care must be determined. In addition, families must notify their district office in advance of service arrangements to confirm availability of funds. It is the family's responsibility to contact the provider and arrange for care. If the family is in crisis or is unable to make arrangements directly, the Coordination will provide assistance. Families are expected to pay in full for care and submit request for reimbursement to the state (there are occasional exceptions where families are not required to pay directly).

Implementation Issues: Arizona currently does not have a formal system for interagency cooperation and collaboration. Because the needs of individuals and their families cross so many service lines, the lack of effective coordination among agencies means there are people needing services who fall through the cracks or who are not assisted until they are in crisis (i.e. seeking an out-of-home placement).

Medicaid Policy: Arizona has recently received a Community and Home-Based Waiver. This waiver is used to help fund respite care. For additional information about Medicaid issues contact: Gale Bohling, Special Projects Coordinator, Division of Developmental Disabilities, P.O. Box 6123, Site Code 719A, Phoenix, AZ 85005, (602) 258-0419.

Related Efforts

SKIP (Sick Kids Need Involved People). Arizona has an active chapter of this organization which offers support, information, education, and advocacy for families who have children with extraordinary health care needs. Information may be obtained by contacting the Arizona Chapter of SKIP, P.O. Box 41274, Phoenix, AZ 85080, (602) 242-2289.

Pilot Parents. The Division of Developmental Disabilities has contracted with this organization for the development of peer self help groups. For more information contact: Mary Slaughter, Pilot Parents, 2150 E. Highland Ave. #105, Phoenix, AZ 85016.

The Administration for Children, Youth, and Families. This agency provides child protective services and funds day care for income eligible families. It also has a strong intervention program for families whose child is at risk of being removed from the home. For information about services provided through this agency contact: Marsha Porter, Director, Administration for Children, Youth, and Families, Department of Economic Security, P.O. Box 6123, Site Code 940A, Phoenix, AZ 85005, (602) 258-0419.

Evaluation: An administrator at the Division of Developmental Disabilities describes the Assistance to Families as the "most successful program we have going". The program is described as a cost effective way to provide services to families. In an evaluation of Assistance to Families, participants credited the program with making a positive difference in their ability to maintain their family member in either their home or in a semi-independent setting. Based upon survey responses from families and case managers, this program appears to contribute to the prevention of out-of-home placements and to enable adults with disabilities to live more independently. The program has been able to assist families financially, relieve family stress, allow for greater independence for the person with disabilities, and enhance the quality of family life. Criticisms of the program include the amount of paperwork required and the lengthy wait for reimbursement.

The design of respite care services appears to be unnecessarily cumbersome and bureaucratic. The current method of requiring families to check in with their regional office prior to arranging for care and to pay up front for respite makes this service less than user friendly. In addition, the requirement to use only providers licensed by the Division takes control for respite away from families and potentially eliminates providers the family might otherwise choose to utilize.

Services for families who have family members with special needs other than developmental disabilities are few. Arizona ranks last in the nation in its funding for mental health services. Even though a decision coming from a class action suit has directed the state to provide services for children with mental health problems, the Arizona state legislature to date has not appropriated the needed money.

Future Directions: The Division of Developmental Disabilities has reported that family support is the major goal in Arizona. It is their hope that in the future a higher percentage of their budget will be directed at strengthening and supporting families.

Lessons Learned: The Division of Developmental Disabilities advises those states interested in developing family support to have families involved from the very beginning in developing services. Wherever possible, families should have control over deciding what services and resources will best meet their needs.

Material Reviewed

Assistance to Families, Program Description and Procedures, Arizona Division of Developmental Disabilities, July 1989.

Cook-Dixon, Marjorie and Prather, Alice, Assistance to Families, Program Report, Arizona Division of Developmental Disabilities, December, 1987: February, 1988.

Interoffice Memo: Family Support Statement, Arizona Division of Developmental Disabilities, May 12, 1989.

Respite/Sitter Services Handbook, Family Support, Arizona Division of Developmental Disabilities.

Title 36. Public Health and Safety, Chapter 5.1 State Department of Developmental Disabilities.

ARKANSAS

Name of Program: Arkansas Family Support Project

Nature of Program: Pilots

Date of Implementation: 1988

Administering Agency/Contact Person: Funding comes through Arkansas Developmental Disabilities Services (DDS) contact: Karan Baker 501-682-8677. For more information on the two individual pilots, contact:

Camp Aldersgate
2000 Aldersgate Road
Little Rock, AR 72205
501-225-1444
Lynn Baker, Coordinator

Family Supports, Inc.
P.O. Box 697
Bentonville, AR 72712
501-273-0338
Pam Biesiot, Coordinator

Type of Program: Cash subsidy.

Number of Families Served: Approximately 36.

Eligibility Criteria: The individual requires extensive on-going support in more than one major life activity in order to participate in integrated community settings. The child must be under 18 years of age with the family committed to community integration, planning to bring their child home from an out-of-home placement, or the child is in a transitional stage. Families must also reside in one of seven counties which are in the pilot-targeted areas.

Services Covered/Allowable Expenditures: The program will fund almost anything not obtainable from other funding sources. Items include but are not limited to the following: respite, wheelchairs, positioning devices, specialized clothing, environmental modifications, specialized medical equipment/supplies, communicative devices, ramps/lifts.

Limit on Benefits to Individual Family: $5,000 per family per year.

Current Funding Level: Approximately $200,000 for each of the two pilots.

Note: Since they have not received funding these programs
will end at the end of the current fiscal year.

Background: The family support pilot projects began in Arkansas approximately one year ago in response to funding policies which inadvertently encouraged the break-up of families. Through Developmental Disabilities Services (DDS), a small amount of money was pulled together and the two pilots were initiated in two separate areas of the state: one through a traditional provider and the other a group of parents who incorporated to establish Family Support, Inc. The program is modeled after the family support program in Madison, Wisconsin. Each program has one paid staff member who works with the focal person outside of her home. The program was very successful and continued into its second year through parental organization and pressure at the state level. The program is not, as yet, a line item in the state budget, but has been funded again this year and has seen an increase in funds. With that increase, there will be attempts this year, to use some of the increase to work with other groups of parents in the State of Arkansas setting groundwork for future programs.

The project will provide an average of $5,000 in supports during the project year to eligible families. Funding above this limit may be provided if approved by the board, which is made up in a large part of parents. It is designated that five to seven of the board members be parents of children with disabilities at least three of whom are receiving support from the projects. In addition, families remain eligible to receive other benefits such as medical assistance, rent subsidies, etc., and/or other program available to community members. The distribution of funds depends on the needs and desires of the families and can include the project taking complete control for the payment or a combination of project funds and existing subsidies.

The projects' coordinators discuss options with each family. Supports not purchased directly by the project are documented through receipts from the family. All supports are listed in the family's Individual Family Plan.

Both groups piloting the project, have been aggressive about disseminating information related to the project. Many have spoken around the state to gain support and attempt to involve parents in other areas.

There is not a stringent monitoring system in place; families are monitoring servcies themselves in most cases.

Implementation Issues: The Family Support Project Board decides on eligibility as well as collaboration efforts with providers to ensure supports are designed around family needs. The families take an active role not only in the development of their Individual Service Plans, but in their implementation. Families may obtain almost complete control over the financial aspects if they desire.

There are at present at least 77 families on a waiting list for services, but in some instances families have not needed the total allocated amount and have given remaining funds back to the program in order to provide support to a greater number of families.

Medicaid Policy: The Medicaid waiver is not being used for family supports at this time and there is no anticipation that it will be in the near future. The

Medicaid waiver in Arkansas is tight and aimed at people with the most severe needs. For further information on the waiver in the State of Arkansas, contact: Cindy Hartsfield, 501-682-8707.

Related Efforts

Department of Maternal and Child Health. This department is involved in some baseline family support efforts related to early intervention. Contact: Dr. Deborah Bryant, Director, 501-661-2199.

Evaluation: Though the Family Support Program in Arkansas is on a very small scale, it is obvious that there is a strong commitment by some individuals toward the development of family supports and parental control of resources. This is demonstrated by the success that has been achieved for a handful of families in a short period of time. It appears that a strong ideology was in place from the start as well as a trust in the abilities of those individuals who would be using the service, namely parents. Much of the program's strength seems to be in the flexibility, autonomy and trust it offers those who are involved.

The program began small but has a well thought out plan for involving additional parents across the state and expanding the program. At this time, funding of the project seems to be the greatest deterrent, yet successes over the past two years as well as the vocal proponents it has created will be instrumental in its future and growth. A strong attempt toward coalition-building with families across the state offers hopeful prospects.

Future Directions: A critical focus, in the state of Arkansas is the need to have legislation passed to legitimatize the budget line for family supports and offer more stability to the program. This is a goal for 1991, and there are hopes that data obtained on the two pilots will offer solid support for the program. It will also be important, as the program grows, to look at alternative funding sources and if expansion occurs, to maintain the flexibility and local control which is one of its present strengths.

Lessons Learned: Starting small has been a very positive aspect of this project. This, along with a strong value base and set standards for what would and would not be offered have helped to make this project a success thus far. Concentration should be on quality rather than quantity. A major strength lies in the extensive control extended to and taken by participating parents.

Material Reviewed

Special Purpose/Construction Grant Application for Camp Aldersgate, Arkansas Developmental Disabilities Services Administrative Services Division, July 1, 1989 - June 30, 1990.

Special Purpose/Construction Grant Application for Family Support, Inc., Arkansas Developmental Disabilities Services Administrative Services Division, July 1, 1989 - June 30, 1990.

CALIFORNIA

Name of Program: Family Support Services

Nature of Program: Legislative mandate

Date of Implementation: 1976

Administering Agency/Contact Person: Developmental Disabilities Services. For information on family support in California contact the State Council on Develomental Disabilities, Rm 100, 2000 "O" Street, Sacramento, CA, 95814, (916) 322-8481.

Type of Program: Purchase of services through the 21 regional centers.

Number of Families Served: 25,000

Eligibility Criteria: Persons must have been labelled developmentally disabled by the definition of the Lanterman Act and be under the age of 18 years.

Services Covered/Allowable Expenditures: Includes, but is not limited to: specialized medical and dental care, special training for parents, homemaker services, camping, day care, short term out-of-home care, babysitting, counseling, mental health services, behavior modification programs, special equipment such as wheelchairs, hospital beds and other necessary appliances, and advocacy to assist persons in securing income maintenance and other benefits to which they are entitled.

Current Funding Level: $30,511,839

Background: Legislation was enacted in California in the early 1960s which initiated a pilot project to test the feasibility of establishing regional centers to serve as a single entry point for assessing a person's needs and obtaining services to meet those needs. In 1969, the Lanterman Act was passed which extended the regional center system through the state and established a system of local area boards to plan, coordinate and monitor community services in the state. The system in the state has since grown to a budget of over one billion dollars. The regional centers are private, non-profit, locally-based community agencies funded and operated under contract to the state, and coordinate a comprehensive service delivery system for eligible individuals, from residential and respite to other individualized supports. The regional centers are the primary point of entry to the service system. The state has 21 regional centers who are responsible for providing services. They also purchase a series of services from approved vendors.

In 1976, Family Support Services were written into law.

Program Structure: The overriding goal in the State of California is to prevent out-of-home placement and allow children with disabilities the opportunity to remain in their parental homes until at least 18 years of age.

Once the person enters the system, the type of service is determined with the case manager in terms of what is needed and what will be received. Through an interdisciplinary team process, which diagnoses and assesses the need for services, an individual program plan is developed. The case manager is a major source of support to the family.

Individual programs are monitored on the local level by 13 separate area boards. These boards are responsible for regional monitoring to protect and advocate the legal, civil and service rights of people with developmental disabilities. They provide local review, resolve local systems problems, perform local planning and program development activities, and conduct public information programs.

A special pilot program of in-home support programs began in fiscal year 87-88 in three regional center catchment areas providing models for in-home and family support to families with children living at home who have severe medical and/or behavioral service needs.

Implementation Issues: Services are coordinated through individual service plans which are prepared by case managers, families and other people that are involved with the person. Supports are decided upon with the case manager and the family depending on assessment of need. The document specifies goals and objectives to meet the person's needs. In some regional areas, parents are asked to contribute between $10 and $500 per month depending upon individual income.

Interagency agreements with many of the state departments have been developed to specify the responsibilities of each agency. Similar agreements are developed at the local level between the regional center and local components of the various state agencies. Area boards as specified by the Lanterman Act

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have also helped to establish a network of collaborative domains within the state.

California has an active and very instrumental network of parents who have called for legislative hearings and drafted legislation.

Medicaid Policy: In the State of California, the Department of Health Services is responsible for the development of appropriate procedures related to Medicaid. There are presently approximately 3,360 individuals receiving services under the waiver. The state also makes use of several other waivers, including Katie Beckett. California is one of the eighth largest users of Medicaid in the United States. For further information, contact: Penelope Stevenson, Department of Health Services/Maternal Child Health, 916-322-2950.

Related Efforts

The Department of Rehabilitation. This department has been a leader in the efforts toward collaboration with other agencies focusing on integration, especially with the Department of Education and Mental Health. Extensive system coordination takes place here. Contact: Roger Chapman, 916-445-3971.

Special Education Department. Contact: Patrick Campbell 916-323-4768.

Mental Health Department. Contact: Ann Arneil 916-323-3801.

Social Services. Child welfare related to in-home supports. Contact: Loren Sutter, 916-445-6410.

Evaluation: Few people in the State of California go without services. When a need is identified, the system kicks into place very shortly. The system is presently operating a variety of services, of which respite has been the one most frequently used. Respite may be difficult to access, if it is not offered at a particular center.

The system itself appears to be able to focus on both individual and cultural differences. California is a state with a wide range of needs and cultural diversity and is very sensitive in its service provision to these issues.

It appears that more individual flexibility and autonomy would better benefit family support programs. The state is moving in this direction and working toward a more decentralized system.

The system of family supports at present, appears somewhat fragmented and lacking in parental control. The state seems committed to a number of future directions that will address these issues. There is an awareness of the weaknesses that presently exist.

Future Directions: There is a move to identify and evaluate potential innovation in family support services that could close some of the gaps in the

California family support service delivery system and implement necessary innovations by the year 1993. These include:

- **Implementation of a voucher system in order to eliminate the middle person and give more direct control to the family is being considered. This would come out of each center's funds for purchase of services.** The **idea is initially to target a small group of families to pilot the program.**
- **Removal of the barriers to the use of effective respite services** by families with children that have medical needs or challenging behaviors will be important to examine, as services have been lacking for these two groups of children.
- Assessment of needs of parents and children with developmental disabilities for training and counseling.
- The development of cost effective approaches to service and furthering the development of interagency efforts of collaboration.
- The education of families in how to use community and personal networks while expanding services through private and community facilities rather than depending totally on the state.

Lessons Learned: It is important to have legislation in place in order to implement a comprehensive program. Looking at community needs and listening to the family constituency help to provide services that are more in tune with the needs and wants of those being served. This is especially important when there are diverse cultural needs.

A commitment to services and the program by the administration is very important.

Material Reviewed

The Alternative Residential Model (ARM), Report on the Pilot Project, Proposal for FY 1987-88. Department of Developmental Services, Gary D. Macomber, Director. April 1987.

Annual Report, 1988. State Council on Developmental Disabilities, 2000 O Street, Suite 100, Sacramento, CA 95814.

California Developmental Disabilities State Plan, 1990-1991 (Draft for initial review, 7/89).

California Regional Center Fair Hearings Appeals Process, An analysis. February 17, 1989. State Council on Developmental Disabilities, 2000 O Street, Suite 100, Sacramento, CA 95814.

Lanterman Developmental Disabilities Services Act (including 1985 amendments) and Developmental Disabilities Assistance Bill of Rights Act (including 1987 amendments). State Council on Developmental Disabilities.

Long Range Plan, 1988-93. Department of Developmental Services, State of California, Health and Welfare Agency.

Shea, J., & Allen, W. Places to live and getting around town: needs, problems, options and possible solutions. Allen, Shea and Associates, 1768 Silverado Trail, Napa, CA 94558. Contract No. 87030, December 12, 1988.

COLORADO

Name of Program: Family Resource Services Program

Nature of Program: Budgeted

Date of Implementation: The Colorado Developmental Disabilities Planning Council, through a grant to the Colorado Division of Developmental Disabilities, initiated the Family Resource Services Program as a pilot project in 1984.

Administering Agency/Contact Person: Lisa Weiler, Division of Developmental Disabilities, 3824 West Princeton Circle, Denver CO 80236, (303) 762-4586.

Type of Program: Reimbursement for services and resources used by the family in caring for their family member with developmental disabilities.

Number of Families Served: 115 families are served as full participants in the Family Resource Services Program; over 200 families receive some support services and assistance through the Family Resource Services Program Special Reserve Fund.

Eligibility Criteria: Limited to families caring for a family member with developmental disabilities, the program has been used primarily to support families with children.

Services Covered/Allowable Expenditures: Families identify their needs and work with a family worker from their regional Community Center Board to develop an annual family plan. Families can be reimbursed for services and resources identified in the plan. Services and resources are those not available through other programs or agencies and are not covered by insurance, Medicaid, or other programs. The program is very flexible in what is allowed for expenditures.

Limit on Benefits to Individual Families: through the Family Resource Services Program, families may receive up to $250 per month.

Current Funding Level: A total of $343,000, $274,000 for annual reimbursement to families and an additional $69,000 for the reserve fund. An additional $80,000 is funded for respite care services provided through four community agencies.

Background: Family support was begun five years ago as a pilot project serving 21 families; by the end of the year the state's Division of Developmental Disabilities had adopted family support as an on-going service. Family support is a line item in the Division's budget and is mentioned in state statute as a specific service.

Developmental disability is defined by Colorado statute as a disability that is manifested before the person reaches the age of 22, constitutes a substantial handicap and is attributable to mental retardation, cerebral palsy, epilepsy, autism, or other neurological conditions when such conditions result in impairment of general intellectual functioning or adaptive behavior similar to that of persons with mental retardation.

Program Structure: Developmental services in Colorado are administered at the local level by 20 Community Center Boards. As stated in the program Implementation Guide for Community Center Boards, the purpose of the Family Resource Services Program is to encourage and support the family in keeping or bringing a child with developmental disabilities home. The program offers financial assistance with the expenses associated with having a child with disabilities, as well as, services to reduce or relieve family stress or difficulties encountered when caring for a child with disabilities.

To carry out the Family Resource Services Program, each Board has a designated Family Specialist, this may be a full-time position or the responsibility of a case manager. The family worker assists families in developing an annual family plan which identifies the services and resources needed by the family. Families are reimbursed by the state, up to $250 per month, for those services outlined in the annual plan. The family worker acts as a broker for services, helping families connect with the providers and resources they need. (With the exception of case management, Community Center Boards do not directly provide support services.) Families with children returning home from an institutional setting or who are on the waiting list for an out-of-home placement are given priority in selection of participants for the Family Resource Services Program.

Case management helps families and individuals access the developmental service system. Case managers tend not to be as informed about the larger social service system. Large case loads, 70 clients and upwards, make it difficult for case managers to find time for the development and utilization of community resources.

Quality control is conducted by the state's Division of Developmental Disabilities.

There is some lack of uniformity from region to region for support services.

Implementation Issues: Funding for family support services is not adequate to meet the needs of families in Colorado. Because the state realizes it cannot meet everyone's needs, there is no active outreach to inform families about these services. Even without promoting family support, the state has over 200 families on waiting lists for the program. Those families who are served report the program has allowed them to take more control over their lives and has reduced family stress.

Medicaid Policy: Colorado has a Katie Beckett Model 50 Waiver which provides assistance to approximately 65 families. In the coming year the state expects to apply for a Model 200 Waiver. Medicaid contact person is: Mark Litvin, Department of Social Services, 1575 Sherman St., Denver, CO 80203, (303) 866-5800.

Related Efforts

Coloradans for Family Support. The state's Developmental Disabilities Planning Council has been instrumental in organizing and supporting this statewide family lobbying effort to increase family support services. This coalition is committed to the following strategies: 1) increasing the funding for the Family Resources Program operated by the Community Center Boards; and 2) introducing a comprehensive family support bill before the Colorado General Assembly in January 1991. The bill would address the current lack of coordination of services and call for provision of family support to Colorado families caring for a family member with disabilities, regardless of what that disability might be.

Permanency Planning for Children with Disabilities. The outcomes of this Council project include: 1) development of family support alternatives to prevent out-of-home placements; 2) increase collaboration between the developmental disabilities and social services systems at the state and local levels to better meet the needs of families and children; and 3) to recruit and support adoptive families for those children who cannot remain with their biological families. Information about both the Family Coalition and Permanency Planning Project can be obtained from: William Gorman, Director, Colorado Developmental Disabilities Planning Council, 777 Grant Street, Suite 410, Denver, CO 80203, (303) 894-2345 (TTY and Voice).

Home Care Allowance. The Department of Social Services administers this small program for families caring for adult family members with disabilities. For more information contact: Department of Social Services, 1575 Sherman St., Denver, CO 80203, (303) 866-5700.

Evaluation: For those families fortunate enough to be participants in the program, Colorado's Family Resource Services provides much needed and valued support. However, the vast majority of Colorado families caring for a family member with disabilities are going it alone. Funding for family support services represents less than one half of 1% of the Division of Developmental Disabilities budget. There are approximately 1,300 children with developmental disabilities in the Department of Social Services system, between 550-600 of these children are in out-of-home placements. The state needs to reevaluate its service priorities. In providing care for its citizens with disabilities, families are the state's greatest available resource; this is a resource that needs to be supported and nurtured.

Future Directions: See Related Efforts Section, Coloradans for Family Support and Permanency Planning Project.

Lessons Learned: In Colorado's experience, the use of a pilot program can be an extremely valuable educational tool in demonstrating the cost effectiveness of family support services. Documentation from other states about their family support efforts can also be helpful in selling family support services. Building a strong, statewide family organization to wage a legislative effort can be a critical factor in initiating or increasing family support services.

Material Reviewed

CDDPC's Memoranda re: permanency planning and grassroots organizing, Colorado statute Article 10.5, Care and Treatment of the Developmentally Disabled.

Colorado Division of Developmental Disabilities Family Services Program Implementation Guide for Community Center Boards.

CONNECTICUT

Name of Program:
1) Respite Care
2) Parent Subsidy Aid Program
3) Demonstration Family Support Grant

Nature of Program: 1) Respite Care is a budgeted line item in two different state departments, 2) Parent Subsidy Aid: budgeted program, 3) Family Support Grants are pilot programs in two different state departments.

Date of Implementation: 1) Respite Care, using other than state employees, was initially funded by the Department of Mental Retardation in 1983; 2) Parent Subsidy Aid Program: Fall 1988; 3) Family Support Grant Program was initiated in the Department of Mental Retardation in November, 1988. A replicated pilot program will be initiated by the Department of Human Resources in 1990.

Administering Agency/Contact Person: 1) Respite Care and Family Support Grants for families caring for a family member with mental retardation: Terry Cote, Department of Mental Retardation, 90 Pitkin St., East Hartford, Ct. 06108, (203) 725-3857; 2) Respite Care for families caring for a family member with a disability other than mental retardation: Carole Christoffers, Department of Health Services, Respite Care Program, 150 Washington St., Hartford, Ct. 06106, (203) 566-1071; 3) Parent Subsidy Aid Program and Pilot Family Support Grants for families caring for a family member other than mental retardation: Mr. Pat Figueroa, Department of Human Resources, 1049 Asylum Avenue, Hartford, Ct. 06105, (203) 566-4580.

Type of Program: 1) Respite Care provides temporary care either in or out of the family's home; 2) Parent Subsidy Aid provides an annual subsidy to be used for disabilities-related needs or services not covered by insurance or other sources; 3) Demonstration Family Support Programs provide monthly cash assistance to a limited number of families.

Number of Families Served: 1) Respite Care: In FY 1988/89, 646 natural or adoptive families and 336 foster families were served by Department of Mental Retardation and 443 families were served by Department of Health Services; 2) Parent Subsidy Aid Program: 37 families; and 3) Pilot Family Support Grants Programs: 18 families served by Department of Mental Retardation and 18 will be served by Department of Human Resources.

Eligibility Criteria: 1) Respite Care and Pilot Family Support Grants: The Department of Mental Retardation serves persons whose primary diagnosis is mental retardation or autism, the Department of Health Services serves persons with other disabilities. For the family support grants, families must be caring for a son or daughter whose disabilities have an extraordinary financial impact on the family over and above typical living expenses. Families with an annual income up to $58,800 are eligible for the program; 2) Parent Subsidy Aid Program: families caring for a child (under 18 years of age, or under 21 years of age if in full time attendance in a school or job training program) with a disability (mental and/or physical impairment that results in substantial, functional limitations in mobility, self direction, capacity for independent living, and economic self-sufficiency). Families are eligible for the program if they plan to return an institutionalized child home or if their child is at risk of being institutionalized.

Services Covered/Allowable Expenditures: 1) Respite Care: Department of Mental Retardation provides or reimburses families for respite care, amount of respite and allowable rate are negotiated with case management at the regional office; in the Department of Health Services grants are awarded to agencies which coordinate respite services; 2) Parent Subsidy Aid Program provides annual subsidy to cover goods and services not covered or reimbursable by insurance or other funding sources; 3) Pilot Family Support Grants: Families use of cash assistance is totally at their discretion; they are required to report how they used the funds.

Limit on Benefits to Individual Families: 1) Respite Care (operated by Department of Health Services): During a year families cannot receive more than 30 days or 720 hours of respite care. Families receiving respite must pay a minimum fee based on a sliding scale; 2) Parent Subsidy Aid Program: Assistance cannot exceed $2,000 in a given year; 2) Pilot Family Support Grants Programs: Enrolled families receive $236.00 per month.

Current Funding Level: 1) Respite Care: FY 1988/89 $400,000 (Department of Health Services) and $799,472 (Department of Mental Retardation); 2) Parent Aid Subsidy Program: Less than $74,000; 3) Pilot Family Support Grants Programs: FY 1988/89 $50,000 (Department of Mental Retardation) and $50,000 (Department of Human Resources).

Background: A number of state departments provide services to Connecticut families. The means and abilities to provide supports to families caring for a disabled family member vary widely depending on the department funding the service and the region where the family lives. Through an interagency agreement, the Department of Mental Retardation provides respite to individuals with retardation and autism and their families, the Department of Health Services serves individuals with disabilities other than mental retardation and autism. In each recent years the Department of Mental Retardation has developed a stronger community orientation and become more responsive to families' needs. A variety of pilot projects benefitting families have originated with this department.

In the past year the Department of Human Resources has been designated the lead agency for people with disabilities in the state. Connecticut's Division of Vocational Rehabilitation has recently been placed under the Department of Human Resources. How and if other Departments within the state bureaucracy will be affected by this designation is yet to be determined.

Program Structure: The Department of Mental Retardation has six regional offices across the state. Two regions have family support coordinators on staff, each region has some component of family support services. Individuals and families access services through case management. Respite care represents the largest service available to families. Families may make arrangements directly with respite care providers and are reimbursed by the state, at an agreed upon rate, for the service. With the exception of spouses, families may use relatives to provide respite care. If requested, training for providers is available from the regional offices. Case managers are able to provide some assistance to families in locating providers. The Department will make respite arrangements for families who are unable to their own arrangements. Each of the Department's Regional Offices has strong family representation on their Advisory Boards. In addition, special and pilot projects initiated by the Department involve families in planning and advisory capacities.

Implementation Issues: While services are standardized in Department of Mental Retardation guidelines, each of the six regions has its own priorities. Regional decisions concerning resource allocations vary, with some regions placing a heavier emphasis on family support than others. Case management case loads are large, especially for case managers working with community clients and their families (case loads can be as high as 70 or more). Regional staff could use additional training in families issues and in connecting individuals with their communities.

The Department of Health Services also funds services to families, primarily through its respite care program. However, because of complications in its funding process this Department has been unable to utilize all its respite dollars and at the end of fiscal year 1987/88 returned $140,000 of respite money to the general fund. The Department of Health Services contracts for respite with private agencies who must provide a 50% match for these state dollars; many agencies are unable to meet this match and consequently allocated dollars go unused and families are not served. Other problems documented with this Respite Care Program include: Difficulty in locating "out of home" beds; families unwillingness or inability to pay a fee for respite services;

agencies inability to hire staff due to labor shortages; agencies discouraging families from requesting weekend respite; and agencies regard respite as secondary to their other services.

Medicaid Policy: Connecticut has a Katie Beckett option which serves a maximum of 50 individuals annually through December 31, 1991. The state also has a Home and Community-Based Waiver which it uses to help fund its developmental services system. More information can be obtained from: Commissioner Lorraine Aronson, Department of Income Maintenance, 110 Bartholoemew Avenue, Hartford, Ct. 06106, (203) 566-4978.

Related Efforts

In addition to those services already discussed, the state's **Department of Mental Retardation** is implementing a small deinstitutionalization project to provide financial assistance to 20 Connecticut families who are bringing a family member home.

Adaptive Devices Program. While this DMR program is primarily used by individuals living in residential programs, some people living with their families do benefit from it.

Family Empowerment Project. The state's Pediatric Research and Training Center provides this program to assist families in locating and obtaining services.

Family Coalition. The Center has also been active in creating this statewide lobbying and peer support group. The Coalition is working in the legislative arena to increase dollars for services and to put into Connecticut law strong language supporting families. Contacts for the Center are: Molly Cole, Family Empowerment Project and Nancy Orsi, President, Family Coalition, Pediatric Research and Training Center, University of Connecticut Health Center, The Exchange: Suite 164, 270 Farmington Avenue, Farmington, Ct. 06032.

The Developmental Disabilities Council. This agency has funded grants to develop circles of support for individuals with disabilities. A circle of support is a group of people who agree to meet on a regular basis to help a person with disabilities accomplish certain personal visions and goals. Individuals who are a part of the circle agree to help the "focus" person overcome obstacles and open doors to new opportunities. In the spring of 1989 there were 40 circles of support operating in the state. Information may be obtained from: Edward Preneta, Executive Director, Developmental Disabilities Council, 90 Pitkin Street, East Hartford, Ct. 06108, (203) 725-3829 (voice), 725-3921 (TDD) or from Beth Mount, Communitas Inc., 73 Indian Drive, Manchester, Ct. 06040.

The Casey Project. The Department of Children and Youth Services has recently received $3 million in foundation and state dollars to implement this pilot program in the New Haven area which provides intervention services for families who have children at risk of being institutionalized. For more information contact: Commissioner Janice Gruendel, Department of Children and Youth Services, 170 Sigourney Street, Hartford, Ct. 06105, (203) 566-3537.

Evaluation: Connecticut's services are becoming more responsive to families caring for a family member with mental retardation. The Department of Mental Retardation has adopted a strong family support philosophy and is working to see that its services to families are expanded. Changes in this Department's respite care regulations and its implementation of the Family Support Grant pilot program, indicate a willingness by the Department to give families control over decisions about how services and supports should be provided. The Department, however, is not adequately funded to meet family needs. Better services and supports for families who have a family member with challenging behaviors or complex medical needs are especially lacking. Those in the system who work directly with families could use more training in family issues and how to achieve real community integration.

The Department of Human Resources adoption of the Family Support Grant Program (as a pilot for assisting families caring for a family member with a disability other than mental retardation) is a good indication of this agency's willingness to be flexible and responsive in helping families meet their needs.

As already stated, the Department of Health Services has had difficulties in providing respite services to its families. Their method of contracting for services must be reevaluated and changed if families are to benefit from agency service dollars.

Through the work of the Family Coalition, Connecticut families are becoming better united and organized in their efforts to improve services.

Future Directions: Connecticut will in the coming year be presenting the findings of its pilot Family Support Grants Program and hopefully extending this services to a greater number of the state's families. The Department of Mental Retardation will be providing greater training for its regional staff in the areas of family support and community integration.

The Family Coalition will be lobbying the legislature for increased financial support for families, as well as a state law adopting the principles of family support.

Lessons Learned: In its work with families, the Department of Mental Retardation cautions against making families dependent upon the state. They advise establishing both good state services and assisting families in utilizing community resources and developing their own natural supports. Services offered to families should put the control in the hands of the families not in the hands of the state. It is important to acknowledge that families know best what their needs are.

Material Reviewed

The DMR Mission, State of Connecticut Department of Mental Retardation.

Family Support Grant Program Service Guidelines.

Department of Mental Retardation Respite Care Guidelines.

Family Support Grant Program, Interim Status Report, July 1989.

"Policy Analysis of Individual and Family Support in Connecticut", this document was supplied by the Developmental Disabilities Council.

DELAWARE

Name of Program: Statewide Respite Program

Nature of Program: Legislative mandate

Date of Implementation: 1988

Administering Agency/Contact Person: Department of Health and Social Services (DHSS), Priscilla Bldg., P.O. Box 1401, 156 S. State Street, Dover, DE, 19901

Type of Program: Respite Services

Number of Families Served: 67

Eligibility Criteria: Families are assessed fees up to one-third the cost of service based on household size and family income; 33% of families pay full charge. Persons eligible are those deemed aged, disabled, physically handicapped or mentally ill (specific types are listed in statewide status report).

Services Covered/Allowable Expenditures: Respite

Limit on Benefits to Individual Family: No more than 216 hours of respite per year, no more than 72 hours per occasion in the home and up to one week in out-of-home care.

Current Funding Level: $75,000

Background: In 1988 the General Assembly passed funding of $75,000 in the budget of the Department of Health and Social Services to establish a program to provide respite services to families with members who were labeled aged, disabled, physically handicapped, or mentally ill. The Department's Long-Term Care working group was charged with overseeing the implementation of a new five-year plan to provide community based long term care services to people that are elderly people with disabilities. Respite was identified as crucial to family support.

Guidelines were developed through a working group and reviewed by the Division. Requests For Proposals were then made to private agencies under contract with DHSS. Proposals were reviewed by a multi-divisional team and the Visiting Nurse Association of Delaware was selected through a bidding process to operate the program. It began in December 1988.

Program Structure: The Delaware Respite Program has two over-all goals: To prevent/delay institutionalization of people with disabilities, and to relieve caregivers.

The program is structured to provide two types of respite care: 1) in-home respite on an hourly basis and 2) out-of-home respite on a daily basis.

The type of respite received, is determined by the desires and needs of the family as well as professional assessment conducted by agency staff. Upon completion of an assessment an individualized care plan is developed, which specifies the type and extent of respite to be provided.

There has been little focus on family support in the State of Delaware aside from the respite program. There is presently a good deal of planning occurring in the state focusing on deinstitutionalization. The state had previously referred people to out-of-state placements and is now attempting to bring them home.

Implementation Issues: Those groups targeted to receive respite services were those for which there is insufficient or non-existent funding from other sources. In order to determine who these groups were, information was gathered on all respite programs funded by the department in the past. Those determined to receive the smallest amount of funding were people labeled physically disabled and/or multiply handicapped, thus they became the focus of this program.

Families are assessed fees based on their ability to pay with the limitation that this be held to one-third of the total cost. There is a feeling that the fee involved will open respite services up to a larger number of people. It is unknown whether a waiting list exists.

A survey completed by the Delaware Respite Care Committee regarding the need for respite services indicated that people were presently using family members and/or neighbors to provide respite for them; and most were unaware that any service existed.

Medicaid Policy: The Medicaid waiver has been used in the State of Delaware to support several people with the label of cerebral palsy in their homes. State Medicaid policy provides optional services such as clinical services, skilled nursing facility services for persons under 21 years of age, transportation, private duty nursing, home and community services for people labelled mentally retarded and those that are elderly or in need of hospice care. For further information Contact: Katie McMillan 302-421-6135.

Related Efforts

Division of Public Health, Handicapped Children's Section. Provides further information related to respite programs. Contact: Jack Fischer, 302-736-4735.

Children's Mental Health. This department has pilot programs in case management. Family Preservation Project, Contact: Patrick McCarthy, Division Director, 302-633-2670.

Division of Mental Retardation. Focus on transition from school. Post 21 program. Contact: Dr. Joseph Keyes, 302-736-4386.

Parent Contact. Parent Information Center, Contact: Marie Ann Aghazadian, 302-366-0152.

Evaluation: At this point, the State of Delaware appears to be somewhat fragmented in regard to family support services. Though recent efforts toward respite services appear to be a positive step, it is only beginning to address the needs of families. There appears to be little thought related to progressive family support efforts outside of the respite program.

The majority of people being served have a physical disability or a label of multiply-handicapped and three-quarters of these are people 60 years of age or older. While this has benefits for these individuals, there remains a large population without any respite services. As indicated in a recently conducted survey, many families have used family members or relatives as respite providers. These natural forms of support should be supported in the future of the Delaware program.

A major difficulty for families is that because of the lack of waivered services and a good number of people without money for insurance and health care, there are many people with no or limited services. Though collaborative efforts have been attempted, there appears to be a lot of disorganization between departments. Efforts to break down barriers and create inter-division projects that focus on the strengths of families are beginning to be addressed in the state.

Future Directions

- Expansion of respite services, case management and health care, provoked in part by the experience of providing respite care to medically fragile children.

- Pursuit of the availability of public and private funding sources for respite care and an investigation of the use of sliding fee scales.

- Development of an awareness program for families to acquaint them with the possibility of services.

Lessons Learned: There should be more extensive, collaborative efforts in the preparation of any support program as well as clearer ideas related to providing services within each department.

Materials Reviewed

Delaware Medicaid Program Blueprint: A Multiyear Perspective. Division of Social Services, Department of Health and Social Services, 1989.

Report, Delaware Respite Care Committee, May 31, 1988. Helen Diskau, Chairperson.

Statewide Respite Program, Status Report. Submitted to Joint Finance Committee, Senate Committee on Health and Social Services/Aging, House Committee on Human Resources of the Delaware General Assembly. Prepared by Division of Planning, Research and Evaluation, Department of Health and Social Services. April, 1989.

FLORIDA

Name of the Program: Independent Family Living (IFL)

Nature of the Program: The IFL program is legislated under the Chapter for Developmental Services, Chapter 393, Florida Statutes.

Date of Implementation: 1969

Administering Agency/Contact Person: Department of Health and Rehabilitative Services, Kathee Winstead, Developmental Services Program Office, (904) 488-4606.

Type of Program: The IFL provides or contracts for direct services to the client and their families.

Number of Families Served: The number of persons being served for FY 1988 was 11,336.

Eligibility Criteria: The IFL does not exclude families because of income or age of the disabled family member. While the IFL program is specifically designated to serve persons with mental retardation or children under 5 years of age who are diagnosed to be at high risk of developmental disability, the same services are available to persons with cerebral palsy, autism, or spina bifida. Onset must occur before the age of 18.

Services Covered/Allowable Expenditures: The primary service provided by the IFL program is case management. Monies have been used to purchase therapies, supplies and equipment, medical/dental care, developmental training, supported and extended employment services, counseling, behavior management training, and other services related to the care of the person with the disability.

Limit on Benefits to Individual Family: There is no limit to the benefits a family may receive. Services are based on priorities of the clients, their families and the resources available.

Current Funding Level: The level of funding for FY 1988 was 11,285,234.

Background: The IFL program grew out of the efforts associated with the implementation of the Community Retardation Act of 1969, the focus of which was to return individuals to their home communities from major state institutions. As individuals returned to their communities, resources were developed or expanded to meet their needs. These expanded resources also served individuals who had always lived in the community. During the 1973-74 state fiscal year funding was provided specifically to purchase services for persons living in their own or their family's home. In 1977 the Family Placement Program was established in law to provide direct reimbursement to families providing care to a disabled family member who returned to his or her home from an institutional placement or for whom institutional care would have been sought were this program not available. During the years since the program was implemented, it evolved from requiring a link to institutional placement to any residential placement supported by the state. During the 1989 legislative session the Family Placement Program was renamed the Family Care Program and the link to residential placement was eliminated.

The IFL is a state-wide program provided by the 11 district offices of the Department. The goals of the program are to move the most capable people to the greatest level of independence, support families in order to keep a disabled member at home when it is in that person's best interests, and promote maximum use of generic services.

Program Structure: The IFL program in Florida provides a comprehensive array of services to families. Every family regardless of income receives case management services provided directly or contracted out by the local district office. The role of the case manager is to develop an Individual Habilitation Plan (IHP) and assist the family in meeting identified needs. Exploring the use of generic community resources is encouraged as a first option. If the service is unavailable through those means then the case manager arranges for the service on a contractual basis. A family is limited by the extent to which a particular service (e.g., respite care) is available in the family's geographical area.

Florida's outreach efforts are extensive. The program is publicized through the ARC's, hospitals, schools, social service agencies, the Parent Education Network, and word-of-mouth.

The IFL is a flexible program and aimed at meeting the needs of the individual and the family. Funding is dependent on an allocation formula and varies from year-to-year and varies from district to district.

Implementation Issues: Florida has a relatively extensive family support program with respect to eligibility criteria and the array of services provided. A person can have one of the following diagnoses; mental retardation, cerebral palsy, autism, spina bifida. Additionally children (0-5 yrs.) may receive services if a diagnosis is not yet confirmed, but they are suspected of having or are at risk for developing one of these diagnoses.

The growth of the program has occurred as expected. To that extent the program has remained stable and consistent. Waiting lists exist depending on the type of service and location. The state tracks the waiting lists by services needed. For example, a total of 3,065 services were needed but not received in the 11 districts by the IFL program. This figure represents a duplicated count and the actual number of families on the waiting list per service is kept at the district level.

Medicaid Policy: Florida has a Medicaid Waiver for individuals with mental retardation who want to live in the community. To be eligible for the waiver the individual must have a primary diagnosis of mental retardation, be eligible for the state Medicaid program, require the level of care of an ICF-MR if community-based services were not provided. This past year 2,631 clients were served under this program.

The waiver reimburses for the following services; case management, speech, physical, and occupational therapies, diagnostic and evaluation services, transportation, developmental day training program, respite care, residential placement services, and family placement services (support services to individuals who live with their natural families). Individuals on the waiver are primarily, although not exclusively, adults who live away from their natural homes. The contact person for the Medicaid Waiver is Denise Arnold, (904) 488-9545, Department of Health and Rehabilitative Services.

Related efforts

Department of Health and Rehabilitative Services. In Florida, family support is primarily located in DHRS, which is the state's largest single department.

The Department of Education. This department is responsible for the 0-2 services; P.L. 99-457. The contact person is Nancy Thomas, (904) 488-6830.

Children's Medical Services. This agency also provides some respite care to families who meet the eligibility requirements. The contact person for the program is Mittie Moffett, (904) 488-6005.

Evaluation: Each of the eleven districts is responsible for monitoring their services. Statistics such as services provided, waiting lists and categories of clients are then aggregated at the state level. The state also has its own mechanism for monitoring service delivery. Additionally, Florida has quarterly meetings. These quality assurance activities help identify problems and resolutions.

Parents play a vital role in developing and planning services. Efforts are under way to improve communication, particularly when other agencies are involved.

One criticism parents have of the program is their mandatory attendance at interdisciplinary planning meetings for the IHP. Specific reasons have not been discussed, but often parents are reluctant to attend meetings of this nature because they are overwhelmed and feel out-numbered. Another criticism is that the services are not sufficient to fully meet the needs. Not only are families on waiting lists to receive services, but many times the quantity of service received does not meet the family's expectations.

Future directions: Florida has proposed a five year implementation plan aimed at expanding and improving the family support program. The plan aims to bring objectives closer to meeting the needs of individuals and their families. The plan is an effort to shift from a "program driven model to a person driven model."

The amount of funding specifically targeted for family supports is expected to increase by 30%-40%. The state plans to develop an instrument and conduct a survey to assess family needs. Finally, Florida plans to develop training for professionals to increase their awareness of the philosophy behind family support. These activities will help the program to take a position equal to other state programs.

In general Florida's program seems responsive to change and is progressing toward a sound family support strategy.

Lessons learned: Florida's system has evolved as a result of many efforts and activities. The informant felt a program must listen to families and be responsive to their needs. Families can best articulate not only what services they need but also how services can best be provided.

Material Reviewed

Developmental Services: Client Services, the Department of Health and Rehabilitative Services, March 1, 1982. (administrative manual describing the background, program structure, and services provided).

Developmental Services Program: 1988-1992, (document submitted to the Florida Legislature by the Department of Health and Rehabilitative Services, March 1988, includes past present and future directions with an emphasis on community base services.

Table J: Developmental Services Waiting List, April 1989, (services are listed by categories and districts; 2 pages).

Copy of legislation: HB 622, Services Relating to Developmental Disabilities, 1989.

GEORGIA

Name of Program: Family Support Program

Nature of the Program: The Family Support Programs (FSP) in Georgia are not legislated by the state. The Programs are appropriated and have state guidelines. Currently the projects are in the pilot phase.

Date of Implementation: FY 1988

Administering Agency/Contact Person: Division Of Mental Health, Mental Retardation And Substance Abuse, Charles Kimber, Deputy Director, Mental Retardation Services; Harry Burkett, Coordinator of Clinical and Support Services, (404) 894-6324 or 6329.

Type of Program: The FSP arranges for contracted services for eligible families.

Number of Families Served: In the first FY, 210 families received services in three Pilot areas.

Eligibility Criteria: An individual with mental retardation (IQ below 70) and substantial functional limitations who lives with natural/adoptive parent(s) or legal guardian may qualify for the FSP. The focus is on families whose income does not exceed $30,000.

Services Covered: 1) Day Care; 2) Counseling/therapeutic/specialized diagnostic services; 3) Dental/Medical services; 4) Specialized Nutrition and Clothing; 5) Specialized Equipment and Supplies; 6) Homemaker Services; 7) In Home Nursing and Attendant care. 8) Home Training/Parent Courses; 9)Recreation/Alternative Activities; 10) Respite Care; 11) Transportation; 12) Other services by written approval.

Limit on Benefits to Individual Family: On the average families receive $2500 of assistance, and assistance cannot exceed $5000.

Current Funding Level: The level of funding is $611,562 for FY 1989.

Background: The Family Support Programs are entering their second year of providing services to families. The pilots represent a move toward comprehensive, coordinated, community-integrated, and family-centered services. The intent of the pilots is to provide support that is meaningful to the family. This effort gives the family a sense of control and a feeling that someone out there cares.

The goals of the program are: 1) to strengthen a family's capacity to provide care for their disabled family member at home; 2) to promote development of family life that resembles family life experienced by families who do not have a disabled member; 3) prevent out of home placement; and 4) enable families who want their institutionalized family member returned home.

The programs are in their pilot phase with a push to make them available state-wide. Thus far the pilots have received a great deal of support from the Governor and the legislators.

Program Structure: The FSP's were expanded to cover 6 of the 27 service areas within the Division of Mental Retardation. Initially 3 pilots were funded. The budget item on the previous page represents 100% state money and funds 6 pilots. The money was disbursed to the six pilot areas on a per capita base, so that some pilots received more funding than others. The numbers of families being served by the 6 pilots for the second FY are not yet available.

The 6 service areas were selected based on previous performance and the quality of care they provided. In other words, service areas with good case management and well developed resources were chosen. In this way the Division could ensure a higher degree of success and assist the pilot Program in expanding to a state-wide effort.

The comprehensive package of services listed on the previous page are geared to meet a variety of individual needs. Each family is given the opportunity to develop their own package of services and prioritize their needs. There is flexibility under #12, which is very much family driven.

Restrictions as to how the FSP dollars are spent are defined in the program guidelines. The primary restriction is that the funds cannot be used to purchase services available through other programs, such as medical care when the person is eligible for Medicare/Medicaid.

Implementation Issues: The state of Georgia restricted its pilots to include only persons with mental retardation. The FSP does not serve individuals with other developmental disabilities as a primary diagnosis. The person must live with natural parent(s), adoptive parent(s) or legal guardian. Foster families or other paid providers of care are not eligible for the FSP. The family income level can not exceed $30,000. Families with an income greater than $30,000 can receive case management services and may be asked to co-pay for some of the services such as respite. All ages are served, although there is a focus on children.

An individual service plan is developed for families who apply for the program. Services are provided to families determined to be most in need. "Prioritizing the families eligible for services will be based on a combination of the following factors: 1) families financial inability to obtain the services; 2) families who are in a crisis situation or under considerable stress; 3) families considering an out-of-home placement and; 4) families planning to bring a person home from an out-of-home placement.

Currently there is a waiting list for services and families receive priority status based on the criteria mentioned above. Additionally the state of Georgia is working with Mercer University to develope a scale/assessment tool that will help identify families with the most intense service needs.

The family support Pilot Projects were promoted primarily at the local level through the mental retardation system. Families who were involved with the program became a good source for recruiting other families.

Medicaid Policy: Georgia has a mental retardation waiver #2106. The waiver covers 8 of the 27 areas previously mentioned. Some of these areas overlap with the 6 pilot areas for the Family Support Program.

The Home and Community Based Waiver has three components: 1) home makers (education and in-service training to families to promote care taking skills; 2) home health aides (provides nursing care to individuals with medical problems); and 3) personal care (episodic care for bathing and other personal care when the family is unable to provide the care.

In addition Georgia has two other waivers. The Community Care Program that provides home-based services to the elderly to prevent nursing home placements. And the "Katie Beckett" waiver which allows medically fragile children to be cared for at home. This last waiver has many restrictions.

The contact person for the Georgia Waivers is Nick Dana, (404) 894-6313.

Related Efforts

The Division of Mental Health and Mental Retardation. This department has the responsibility to provide the family support components mandated in PL 99-457. They are excited about this initiative and they feel confident about their area of expertise. Nineteen teams have been formed around the nineteen regional health departments. The Division of M.H. and M.R. hopes to expand the number of teams to 27 to coincide with their regional offices.

Early Intervention Program. The contact persons for this program are Harry Burkett and Ralph McCuin, (404) 894-6324.

The Community Care Waiver. This is a joint project between the Office of Aging and the Health Department. Its purpose is to reduce the risk of out-of-home placement for the elderly. Family supports are very limited in the WIC Program and Children's Medical Services. The contact person for the Division of Public Health is Dr. Alley, Director, Family Services Unit, (404) 894-7505.

Evaluation: The FSP is a family-focused, family-directed, program. The FSP is flexible and responsible to individual family needs. The families thus far are pleased with the program and some families have reported that "(it) has given them a whole new outlook." The families have experienced more opportunity for community integration, and the services have enabled them to reconnect with extended family and community ties.

Initially the FSP was off to a late start and money was not available until the sixth month of implementation for the first FY. Additionally it is not a state-wide program making it inequitable for many of the families in Georgia. The Family Support Program needs to be expanded to a state-wide program which would necessitate additional funding.

Family supports, although in their initial phase, seem to be a priority for the state of Georgia. As mentioned earlier this program has received the support of the Governor.

Parents were vital to the development of the FSP. They were essential in advocating for funding and the structure of services. Their role needs to be expanded, particularly within the early intervention services. Parents need to have input in the modification and monitoring of services and helping the program become state-wide.

Family supports in other state departments are limited. It is hoped that with the early intervention program these efforts will become more wide spread. Presently, family support is seen as too small to merit interagency collaboration . The informants reported that communication and collaboration mainly takes place at the local level.

Future Directions: The informants were optimistic about the continuation of family supports. They saw this effort expanding to other areas particularly with EI services.

Lessons Learned: The informants felt that starting family supports as a pilot project was a good idea. Pilots help identify problems with the program and are more easily altered in the initial phase. This would enhance the successful implementation of a state wide plan.

Georgia modeled their program after Wisconsin with the exception of the age limitation. Georgia did not want to focus only on children. States must decide on their focus ahead of time.

"Families are the largest service providers for persons with disabilities and the states need to support them as an essential resource for daily care."

Material Reviewed

What's New - The Family Support Program (newsletter, no date).

Guidelines: Family Support Programs,(manual) Georgia Department of Mental Health, Mental Retardation, and Substance Abuse "Community Mental Retardation Services" July 1, 1987 (FY 1988).

HAWAII

Name of Program: Family Support Services

Nature of Program: Legislative mandate

Date of Implementation: 1987

Administering Agency/Contact Person: Developmental Disabilities Division Contact: Lisa Maetani 808-735-5237

Type of Program: Invoice reimbursement

Number of Families: 51 families

Eligibility Criteria: Individuals must meet the Division's eligibility criteria and the DD/MR family member must live in the home which comprises a family. Family is defined by the program as a parent, sister, spouse, son or daughter, grandparent, aunt or uncle, cousin or guardian, or an individual who has become a member of an immediate family through the Hawaiian "Hanai" custom. Ages served are 0-death. There are no income criteria.

Services Covered/Allowable Expenditures: Environmental modifications, limited amounts of family counseling or training, homemaker services, transportation, respite and other services not covered by some other source and supplies and equipment not otherwise covered by another program.

Limit on Benefits to Individual Family: Up to $2,000 per family per year.

Current Funding Level: $115,000

Background: Family supports in Hawaii have been provided for approximately two years. This program was initially introduced and supported by the Developmental Disabilities Council, which stressed the need for such a program for those individuals who did not qualify for Medicaid services. Since July 1, 1989, the Division of Developmental Disabilities is officially responsible for the program.

Program Structure: The main goal of Hawaii's family support program is to help enrich and enhance the integrity of the family experience, and to help families keep their members with disabilities at home and in their local communities. It also attempts to promote self-sufficiency and keep a functional family unit intact.

Families first must apply for services from the Community Services for the Developmentally Disabled Branch. Eligibility for Branch services is first determined; application for family support services is reviewed by the Family Support Services Program worker with whom the family works out a service plan; plans can be amended as new needs arise. Parents/family play a primary role in deciding which services they need. Each participating family can receive up to $2000. Family Support Services Program funds are tapped into only after all other sources and resources have been explored and exhausted. Priority factors are considered in determining a family's receipt of services.

Families are responsible for ensuring quality at this time; the program's responsibility in relation to these issues is to guarantee smooth program operations. If there are providers that the agency lists or recruits, the agency itself does the monitoring. This has been successful thus far, but it is a process to be assessed in the future.

There are some additional respite programs in the state through the Association for Retarded Citizens, but they are mainly recreational in nature. There is also a foster home program for adults and children as well as some use of waivered funds for respite, mainly in Intermediate Care Facilities.

Implementation Issues: Hawaii has a reimbursement system in which services are first purchased by families who are then reimbursed through the submission of an invoice for services received. There is sometimes a delay in reimbursement, and families often have difficulty initially coming up with the money. The state is beginning to look at other options.

The state highly encourages families to use their natural networks. This is an important element in the State of Hawaii, because of the strong family and extended family ties. There are also some private providers of services such as respite. In addition, the Department's foster home program for adults and children is a resource for eligible individuals.

The state has received technical assistance from the Human Services Research Institute who have facilitated the development of family support networks throughout the state in order to develop advocacy and other skills among parents. A second technical assistance grant has been received which will help families to participate in and influence the legislative process.

The primary request for support services has been for respite care. Initially, the assumption was that respite services were in place for families; the evidence is now clear that a respite network needs to be developed. Often, this is accomplished within the community and families.

For the most part, knowledge of the program has been spread by word of mouth and by social workers and/or case managers. There has been no active outreach.

The state has sought technical assistance from National United Cerebral Palsy (UCP) who has assisted them in starting family support networks in order to promote advocacy and other skills among parents. The level of sophistication among parents varies, but overall parents have been very supportive.

Medicaid Policy: Some waivered programs provide some respite services for children needing long-term aid. For more information contact: Geri O'Banion 808-548-2211.

Related Efforts

Education. There are some efforts around P.L. 99-457. Contact: Jean Stewart 808-735-0434.

Maternal and Child Health. Contact: Loretta Fuddy 808-732-0113.

Evaluation: The State of Hawaii is extensively aware of cultural needs and is committed to using community and generic resources rather than establishing service systems that take the family and individual away from the community and extended family.

A major difficulty in the system seems to be the manner in which reimbursement is handled. Because families must initially pay for the services they use, there is a good deal of lag time in the state processing of their submitted bills. This often adds stress to the family.

The degree of flexibility is a very positive aspect of the program, and families seem to have a good deal of control over determining their own needs. This will be important to maintain as the program matures. There is already talk of establishing more restrictions and guidelines.

There is also a major effort to bring parents together and empower them through advocacy training and mutual support.

Future Directions: Future plans for family support efforts in Hawaii are to expand and more clearly define the boundaries of the program and the needs of consumers. There will also be increased efforts to more actively involve families in shaping family support policies. The fiscal mechanism, presently a reimbursement system, is also being evaluated toward a more user friendly design. In addition, the policies and procedures for prioritizing recipients for family support monies are being assessed.

Lessons Learned: It was useful to start with the involvement of families and service providers as early in the planning and program design process as possible.

The conceptual framework should be as flexible as possible. Before the conceptual framework was developed, planners studied the implications of the diversity of cultural needs as well as special family characteristics of Hawaiian people. Models being used throughout the United States were reviewed and then adapted to meet the needs of the Hawaiian people.

Such flexibility has supported a process which is open to perceiving the central needs of consumers. The program needs to begin looking at setting some limits in the face of fiscal problems. This might entail setting limits on service areas, such as establishing the amount a family may spend on respite and other services. The program is, however, still at the point of collecting data and will not set such limits in the immediate future.

Materials Reviewed

Family Support Services Program, brief overview of services in Hawaii.

IDAHO

Name of Program: 1) Respite Services
2) In-Home Financial Assistance

Nature of Program: Ongoing state-funded services

Date of Implementation: NA

Administering Agency/Contact Person: Paul Swatsenbourg, Bureau Chief of Developmental Disabilities, 450 West State: 10th floor, Boise, Idaho 83720, (208) 334-5512.

Type of Program: In- and out-of-home respite services and cash assistance grants.

Number of Families Served: 1) Respite Care: 182 children; 2) In-Home Financial Assistance: 122 families per year.

Eligibility Criteria: 1) Respite Care: individuals for whom respite is provided must have a substantial physical, mental, or developmental disability which prevents normal participation in community and/or life activities as are available to and participated in by persons of the same age and sex who have no such afflictions or conditions. Such disability shall have occurred and been diagnosed prior to age 22. 2) In-Home Financial Assistance: Eligibility is limited to an individual who a) is 21 years of age or younger with a developmental disability; b) eligible or presumptively eligible for Medical Assistance without reference to the income or resources of such individual's parents; and c) has one parents who desires to maintain their child within their home or to return the child to their home from an institution; willing participate in individual habilitation plan; and will keep an accounting of funds for services and equipment. Family income is not a consideration.

Services Covered/Allowable Expenditures: 1) Respite Care: in or out of home care; 2) In-Home Financial Assistance: Monies may be used for, but are not limited to, any of the following items listed in the approved individual habilitation plan: diagnostic and evaluation procedures; purchase or rental of special equipment; specialized therapies; special diets; medical and dental care; home health care; counseling; respite care; child care; special clothing; transportation; housing modifications; and recreational services.

Limit on Benefits to Individual Families: 1) Respite Care: Care may not be used in lieu of normal day care in order for parents or guardians to be employed. Respite care services shall not exceed 18 days and/or nights (432 hours) in any three month period. 2) In-Home Financial Assistance: Maximum financial assistance is $250 per month per family. This limit may be waived in cases of extraordinary need

Current Funding Level: 1) Respite Care: $70,000 and 2) In-Home Financial Assistance: $50,000.

Background: For the In-Home Financial Assistance program a developmental disability is attributable to an impairment such as mental retardation, cerebral palsy, epilepsy, autism, or other condition found to be closely related to these impairments and has continued or can be expected to continue indefinitely and constitutes a substantial handicap to such person's ability to function normally in society. This program cannot be used for payment of educational or educationally related services which properly are the responsibility of the public schools. In addition, no grant under this program shall exceed 33% of the current average cost of ICF/MR care in the state of Idaho.

Program Structure: Developmental and family support services are delivered through local Adult and Child Developmental Centers. Families are members of the planning treatment team and take part in developing the Individual Habilitation Plan which outlines the services and treatment their family member will receive.

1) Respite Care: Regulations for this service state, "It is the Policy of the Department of Health and Welfare to encourage and participate in programs which assist parents or guardians in maintaining handicapped individuals in their own homes through respite care. Respite care may be utilized to meet emergency needs, to maintain or restore the physical and mental well being of the individual's parents or guardians, or to initiate training procedures for the individual's parents or guardians in or out of the home." A list of respite care providers is provided to parents or guardians of eligible individuals. If families choose to use a provider not listed, that provider cannot be a relative of the family or of the individual receiving care. Providers are paid directly by the state at a rate established by the "Respite Care Fee Schedule".

2) In-Home Financial Assistance: Program regulations state, "It is the policy of the Department of Health and Welfare to encourage and participate in programs which assist parents or guardians in maintaining handicapped individuals in their own homes through in-home financial assistance. In-home financial assistance may be utilized to allow the parents of children who are institutionalized or parents of children for whom institutionalization may be imminent, and who will, as a result of the in-home financial assistance grant, return or keep their children home." The Adult and Child Development Centers determine the amount of the grant based upon the parents' and child's needs. Payment to families is made monthly by authorization of an "Expenditure Voucher". Each month families must document their expenditures to the Adult and Child Development Center and develop an Expenditure Voucher for the next month's payment.

Implementation Issues: NA

Medicaid Policy: Idaho has a Medicaid Waiver for Personal Care Assistance, 225 children and adults benefit from services funded through this waiver. Contact person: Lloyd Forbes, (208) 334-5798.

Related Efforts

PL 99-457. Contact for the implementation activities is Cathy Pavisic, (208) 334-5512.

The Idaho Division of Mental Health. This department has no respite services for families; they do have crisis day care and local centers offer parent support groups. Contact person is Dave DiAngelos, (208) 334-5512.

Evaluation: Families who have children with difficult behaviors or severe disabilities have difficulty in finding a respite care provider willing to work at the rate the state pays. The daily rate for children with severe disabilities receiving in-house respite (as opposed to that provided in a day care center, ICF/MR, or Nursing Home) cannot exceed $25 or $2.25 an hour. The daily respite care rate for children with mild or moderate disabilities is substantially less, $15-$18 or $1.50 -$1.75 an hour respectively. In addition, respite care providers must submit an invoice to the state in order to be paid. This requirement means additional time and paperwork for the provider, as well as a guaranteed delay in payment for services. The state's unwillingness to pay relatives for respite care eliminates an important respite resource for families. The respite care service in Idaho seems unnecessarily bureaucratic and takes control away from parents.

Future Directions: NA

Lessons Learned: NA

Material Reviewed

State regulations for Respite Care and In-Home Financial Assistance.

Informant: Paul Swatsenbourg, Bureau Chief of Developmental Disabilities, 450 West State: 10th floor, Boise, Idaho 83720, (208) 334-5512.

ILLINOIS

Name of Program: 1)Respite
2)Family Support Pilots (FSP)

Nature of Program: 1) Respite is a budgeted state program; 2)The FSP's are pilots

Date of Implementation: FSP: FY 1988 (Oct., 1988)

Administering Agency/Contact Person: 1) Department of Mental Health and Developmental Disabilities. 2) Illinois Governor's Council on Developmental Disabilities, Sandy Thurston Ryan, (312) 917-2080.

Type of Program: 1) Respite 2)The FSP is a combination of cash subsidy and a voucher system.

Number of Families Served: 1) 3,147. 2)Two hundred families are being served state-wide; approximately 50 families per pilot project.

Eligibility Criteria: 1) Presence of a developmental disability 2)The FSP in Illinois serves persons of all ages with developmental disabilities. An individual must have a developmental disability and live with his/her natural/adoptive family. The family is allowed an annual income of $50,000.

Services Covered/Allowable Expenditures: 1) In and out-of-home respite 2) Each family receives case management services. This provides the access to the cash subsidy. The cash subsidy may be used to purchase goods and services directly by the family, on a contractual basis with a vendor, or by reimbursement to the family. The goods and services allowed range from traditional therapeutic services to a set of uniquely identified needs by the families. The request for goods or services must be related to the care of the individual with a developmental disability.

Limit on Benefit to Individual Family: 1)180 Hours of respite per year;
2) $3,000 per year.

Current Level of Funding: 1) Respite: $4.8 million 2)The FSP was funded at $320,000 for the first FY.

NOTE: New far-reaching family support legislation was passed at the last session of the state legislature. The department is currently in the process of planning for implementation of this law.

Background : The FSP's in Illinois are independent of the Department of Mental Health and Developmental Disabilities. In 1986, the Department abolished the regional system and organized a central office. The central office then designated non-profit service providers to act as case managers and provide services to persons with developmental disabilities who live in residential facilities as well as in their natural homes. Services include but are not limited to home behavior management training, referrals to other community resources, and respite care. A request for services provided at the local level must be approved by the state Department in Springfield.

Currrently, services in Illinois are fragmented with a great deal of discretion left up to the service providers. Respite care is difficult to access; however, the state has increased fiscal support of the program in the past several years. A family may receive 180 hours of respite care with a 180 hour extension (for special circumstances) per year. A family is eligible for respite care if they have a family member with a developmental disability. There are no restrictions placed on income or age. Respite care is available in almost every county.

The respite care programs are provided by the individual service agencies contracted by the state. There are three models of respite care available in the state: 1) in-home respite care (planned or emergency); 2) residential respite care (out-of-home respite provided by a licensed residential facility; and 3) group/day respite (respite care that is provided after the individuals' school or work program, until the family can resume care).

In summary, the state of Illinois is just beginning to develop a family support program, and is preparing to implement a new comprehensive family support legislation. It is hope that the considerable experience that the Illinois Council on Developmental Disabilities has gained around family support will help guide the implementation of this potentially far reaching legislation.

The Illinois Governor's Council on Developmental Disabilities has funded four Family Support Pilot Projects throughout the State. The Council formed a task force to develop recommendations. They surveyed over 700 families during the course of which two global issues emerged. First, families wanted a system different from existing programs and second, they wanted assistance with future planning.

The FSP projects are beginning their second year of support. The pilots were chosen in four geographical areas around the state; urban, metropolitan, suburban, and rural. Not-for-profit agencies who provide services to individuals with developmental disabilities and their families competed for the funds to administer the projects.

The Council's intent was to introduce new components and expand the notion of family support in the state of Illinois. The goals of the program are: To empower families with decision-making regarding service needs; to enhance the quality of life for individuals with disabilities and their families; and to prevent inappropriate out-of-home placements. It is hoped that the state Department of Mental Health and Developmental Disabilities will pick up the funding for the projects and expand them to a state-wide effort.

Program Structure: The four pilots are administered by four non-profit organizations, each with its own focus and area of expertise. Consequently, they entail a great deal of variety. The pilots are consistent with respect to eligibility criteria and case management services. But differences occur at the administrative level of the organizations where outreach activities, intake procedures, and supervision are varied. The administering organizations have also varied the form of the subsidy such as paying families directly for agreed upon services, reimbursing for out-of-pocket expenditures, or authorizing vouchers with contracted service providers.

The FSP provides families with a great deal of flexibility and control. Case managers meet with the families and develop an Individual Family Service Plan, provide supportive counseling, assist the families in prioritizing their needs, and link families with appropriate resources that are already available in the community.

The Illinois FSP, unlike those administered by the state departments, are independent of their auspice. While this offers the luxury of being autonomous, they must also rely on the state to supplement gaps in services.

Implementation Issues: The FSP is family-driven and attempts to put families in control of determining their needs. The monies used to purchase goods and services must be the last dollar and may not replace other mechanisms of payment, e.g. insurance or Medicaid must be billed for eligible medical care.

Parents are allowed to be creative within the pilots (e.g., purchasing home aides, specialized clothing, etc.). In some instances, families may choose to pay for a portion of an item. This is a more cost-effective use of the FSP and gives the family a sense of ownership. Families are also allowed to use the supports for ongoing services, e.g., therapy, or a one-time expense, e.g., a car seat.

Families were recruited in a variety of ways, e.g., newsletters, social, and health care agencies. At least 50% of the families had to be new to the agencies. The remainder of families could be recruited from already existing case loads. This allowed families who were not otherwise being served to receive family supports.

The DD Council funded the projects for two years.

Medicaid policy: The Department of Mental Health and Developmental Disabilities has a model waiver directed at deinstitutionalizing individuals from state hospitals. The waiver serves 600 people, 98% of whom now live in group homes. The department's contact person is Marie Havens, (217) 782-7393.

The Department of Rehabilitation also has a Medicaid Waiver called the Home Services Program which primarily funds attendant care. This program has served 6,000 individuals, 600 of whom have either mental illness or mental retardation. This department's contact person is Carl Hamilton, (217) 782-2722.

The state of Illinois has a Medicaid Waiver for 100 medically fragile children between the ages of 0-21, funded by Public Aid (PA), administered by the University of Illinois Division of Services for Crippled Children (DSCC). The contact people are Rosemarie Manago, DSCC, (312) 996-3550 and Ray Carmody, PA, (312) 793-2791.

Related Efforts

The Department of Mental Health and Developmental Disabilities administers two programs designed to promote community living though not necessarily family-centered care. The **Supported Living Program** is one program for individuals with developmental disabilities needing minimal supports. The program served 11,650 individuals, 3400 of whom live alone.

The **Family Home Maintenance Program** is a second program aimed at preventing inappropriate residential placements. This program is entering its second fiscal year. It pays for services that help keep a family member with a disability at home. Illinois has a strict review process for accepting a child for residential placement. This program attempts to reduce the risk of out-of-home placement.

In addition this past year the Department funded four family support pilot projects that are each administered by a non-profit agency. The principal components of the pilots are case management services, parent support, education, and training.

The Department of Rehabilitation. This is one of Illinois' most active departments concerned with family supports. In addition to the Medicaid waiver mentioned above, the Department administers a program called Next Step. This program assists high school students with disabilities and their families with vocational and continuing education, independent living, and other transitional services to adult life. The program's contact person is Carl Suter, (217) 785-0218.

The Department of Education. This is the lead agency for the 0-2 services (PL 99-457). They are directing their efforts toward family supports as outlined in the Individual Family Service Plan. The program's contact person is Audrey Whitztman, (217) 524-4835.

The Illinois Department of Public Health. This Department has a Division of Family Health. The contact person for their services is Steven Saunders, (217) 782-2736.

Evaluation: Consumer input at the state level is minimal in Illinois. The FSP Task Force had strong parent representation as does the DD Council Advisory Board. In general parent input has been more effective at the local level.

The FSP 's are being independently evaluated by Human Services Research Institute in Cambridge, Massachusetts. Quarterly reports of service utilization, family satisfaction surveys, and family interviews are being collected and analyzed. The findings from this evaluation will be submitted to the legislature for continuing support at the state level. Additionally, each pilot project uses their agency's internal quality assurance and monitoring standards to assess the programs.

Family Support in Illinois is in its pilot phase, making it too early to assess impact on the families served. Parents have reported general satisfaction with the program and feel it offers alternatives and choices not otherwise available.

Future directions: As mentioned earlier, it is hoped that the FSP will have major influence on the design of the new permanent effort in the state department.

Lessons learned: A family support program must have a clear definition of what services are considered family supports. The program must also be clear about what it will and will not provide. The informant felt that a consensus of definition and services will help build political support.

INDIANA

Name of Program: Independent Living Support Services (ILSS)

Nature of Program: Legislative mandate: I.C. 16-13-22; P.L. 28-1985.

Date of Implementation: FY 1985

Administering Agency/Contact Person: Department Of Mental Health And Developmental Disabilities, Mike Morton, Division of Residential Services, (317) 232-7986.

Type of Program: The ILSS pays directly for services delivered to the family. The monies are almost entirely used to fund respite care.

Number of Families Served: Six hundred families received respite care on a sliding fee scale basis. An additional 500 families paid for the entire amount of respite care received.

Eligibility Criteria: Indiana's eligibility criteria includes people with developmental disabilities under the old federal definition which was categorical. People who have mental retardation, epilepsy, autism, cerebral palsy or a condition closely related to mental retardation are served under the program. For children between the ages of 0-3 the disability guidelines are more inclusive and include children who are at "risk" for a developmental disability. People who have mental illness are also included. There is no age restriction. Nor is there an income restriction since all respite care is offered on a sliding fee scale.

Services Provided/Allowable Expenses: Respite care is the major service provided by the ILSS. Other traditional services are provided at a minimal level.

Limit on Benefits to Individual Family: The family limit for respite care may not exceed $600 per year. Beyond that amount parents have to pay for the service.

Current Level of Funding: The ILSS was funded at $370,542 for FY 1988 and $434,535 for FY 1989.

Background: The ILSS began in 1985. An earlier version of the program was funded by the Developmental Disability Council approximately 5 yrs. ago. This program also primarily funded respite. The state did not continue to fund this project, and there was a gap in services between the time the D.D. Council project ended and the ILSS began.

The goals of the IlSS are: 1) to reduce the risk of a person experiencing an inappropriate out-of-home placement; 2) to reduce the adverse impact of a family-related emergency or crisis in order to increase the long term stability of the family; 3) to support the right of individuals to be appropriately supported in providing a stable and secure home life; and 4) to reduce the stress on the family which may result from the day-to-day care of a handicapped family member.

Program Structure: The Indiana ILSS is a limited program in many ways. Although the policy is intended to be broad and flexible to meet the needs of the family, in practice the program funds respite care. The ILSS's intent is to provide other services such as therapies, supplies, and equipment, but in fact these services are only provided minimally. All services, including respite, are provided on a sliding fee scale.

The program is state-wide, but services vary from region to region both in terms of availability and quality of services. There is no active outreach or coordination of services.

Implementation Issues: As noted before, respite care is the primary family support service offered through the ILSS program. Respite care can be either in-home or out-of-home and over-night or daytime. Respite care may not be provided in an institution. Availability of respite care is dependent upon the funding lasting throughout the fiscal year.

Case management exists throughout the eight state districts. Case managers assist with residential placements. Their case loads are large, and their role is narrowly defined.

In summary Indiana's program does not offer a comprehensive array of services to meet the complex and various needs of families who care for a disabled family member. The program needs to increase its level of funding and expand its availability. More importantly, the program needs to develop other resources to reduce the risk of out-of-home placements and enhance the quality of life.

Medicaid Policy: Currently Indiana is applying for a Medicaid waiver to serve 50 people with Autism. As of this writing it has not been approved. The contact person for the Medicaid waiver regarding developmental disabilities is Vickie Trout, (317) 232-7896.

Related efforts

The Choice Program. Indiana offers this family support program through the Department of Human Services, Aging Services Division. It is aimed at preventing institutionalization of people with disabilities. In the past fiscal year, Choice served 1,192 individuals of whom 20% were under the age of sixty. The FY 1988 budget for Choice was $ 3 million which has been increased to $6.5 million. One criterion of the program is that home care must be less costly than institutional care. The Choice Program is well funded and very flexible in meeting an individual's needs. It is available in 20 of Indiana's 92 counties.

Disabled Children's Program. This SSI agency provides case management services, respite care, parent education, counseling, and information and referral. Currently it is administered under Public Welfare but will move to the Board of Health, The contact person for the Board of Health, MCH programs is Diane Downing, (317) 633-8457.

First Steps. This is the state's infant/toddler program under P.L. 99-457. The program, administered under the Department of Mental Health, is responsible for the family support/participation components. The contact people are Dorie Bedwell and Donna Olsen, (317) 232-3097.

The Department of Education. This department is responsible for the special educational services offered to the 3-5 yr. olds. Paul Ash, (317) 232-0570 is the contact person.

Evaluation: The services offered in Indiana's ILSS are somewhat under-developed. This is also true with respect to parental involvement in program planning. Currently there is no formal complaint system or resolution process. Parents are not given an opportunity to plan or develop services on an individual basis. Indiana has a new state administration, and it is felt that parental participation will increase. A priority is also being placed on coordinating services.

The state has quality control for respite care providers, who must meet certain standards and training requirements. Occasionally, there are on-site reviews, but they do not happen often enough. The program could be monitored more effectively if more staff were available. The current system is fragmented and many resources exist which are not well known. Indiana has a great need for a referral and information system.

Future directions: In spite of the Indiana ILSS's short comings it has the potential to become a solid program. Policy and philosophy exist, but implementation is lacking. Other areas of service for family support need to be developed and expanded.

Lessons learned: A sound family support system must start with an adequate level of funding. The system must also include consumer input and have a strong family coalition. Finally, states need to be aware of existing community programs and resources and have a plan to develop them if they do not already exist.

Material Reviewed

Department of Mental Health, Administrative Directives on "Independent Living Support Services", April, 1987, (policy manual).

IOWA

Name of Program: Family Support Subsidy Program (FSSP)

Nature of Program: The FSP was enacted in the Iowa state legislation in April 1988, Senate File 2018.

Date of Implementation: FY 1988

Administering Agency/Contact Person: Department of Human Services, Sally Cunnigham, (515) 281-6360.

Type of Program: The Iowa FSSP provides a direct cash subsidy to the families who have a disabled child living at home.

Number of Families Served: 54 families were served the first year.

Eligibility Criteria: Children served under the FSSP are the most severely impaired as certified according to their special education district's rules. The program serves children who are under the age of 18. Family income may not exceed $40,000.

Services Covered/Allowable Expenditures: Families may use the subsidy at their own discretion.

Limit on Benefits to Individual Family: Families receive $246 per month.

Current Funding Level: FY 1988 received $75,000. This increased to $400,000 for FY 1989.

Background: The Iowa FSSP came about as a result of family advocacy and support from former Senator Holden. A task force comprised of consumers and professionals received technical assistance from Michigan. The program was modeled after the Michigan family support program but on a much smaller scale.

The goal of the program is to reduce out-of-home placement of children.

Program Structure: Even though the program is small in scale, the Iowa FSSP is available state-wide. Iowa has eight district offices in the Department of Human Services, and the money was divided equally among them. The program is available on a first-come, first-serve basis. Neither the program nor the district offices had extra money for publicity, so outreach activities were kept to a minimum. If parents were connected to other services they were more likely to find out about the FSP.

The cash subsidy component offers a great deal of flexibility. Parents can use the money at their own discretion for the special needs of their child and the family. For example one parent used part of the money to pay for tuition which enabled her to compete for better jobs. Another family used the money to pay for car repairs which were necessary to make doctor's appointments and other travel needs.

The money may not be used for already existing services or services that are covered by other means. For example, the cash subsidy may not be used to cover a medical expense if the child has insurance or Medicaid.

In general, families receive the monthly stipend of $246 per month. In some cases families were given a two month lump sum for start-up costs.

Implementation Issues: The FSSP did not provide money for administrative costs and volunteers were used to assist with intake and to process applications.

The program is targeted for the most severely impaired children. One criterion consists of a weighting scale used by the Division of Special Education in the Department of Education. The child must qualify in one of the upper 2 of 3 specified categories. Children with physical impairments may not qualify unless they meet the additional criteria of these categories.

The program has grown financially as the budget indicates, but it is premature to assess effectiveness in any detail.

Medicaid Policy: Iowa has a Title XIX Home/Community based waiver. It serves 200 adults and children, whereas the FSSP only serves children. The focus of the program is to provide case management services and assist families with accessing community resources. Individuals on the waiver must have mental retardation or a mental illness. Adults primarily have access to case management services, and children have access to family services which provide support in the home. The waiver provides family support services and is another program which allows disabled persons to remain in their home.

The "Katie Beckett" Waiver originated in Iowa and was named for a little girl with medical complications. This program is geared toward assisting families who care for the medically fragile children at home.

The contact person for the Medicaid Waiver is Kathy Keller, (515) 281-5487.

Related efforts: Family support activities in other agencies are very limited.

Early Intervention. The state has an interagency coordinating council and their primary focus is P.L. 99-457, 0-2 services. The Department of Education is the lead agency for that program. The contact person is Joan Clarey, (515) 281-5614.

Iowa has a University Affiliated Program that provides some family support activities. The contact person is Al Healy, (319) 353-6390.

Evaluation: Iowa's program is relatively new and is in its beginning stag. The cash subsidy gives the program a progressive aspect. The money is given with few restrictions. One persisting criticism is the lack of community resources. For example, respite care which is offered privately or county-by-county is very sparse, making this service difficult to access even with the subsidy. Other services are equally unavailable for parents to purchase.

Another often-cited limitation is an income eligibility level that is too low. Some middle income families, for example, are not eligible. A third limitation is the exclusion of adults and people with physical and/or moderate disabilities.

One strength of the program is the flexibility offered to parents through cash assistance. This feature enables parents to make their own choices and meet their needs on a truly individual basis. Second, the FSSP is legislated. And finally, the program is state-wide so that families are not discriminated against by geographical location.

Initially, the program was implemented with minimal consumer input. Presently, the role of parents and consumers has grown, and their input is becoming more significant. At the local level parents participate through the Area Education Agencies.

Monitoring of the program and quality assurance activities are not yet developed. Evaluation of the program has taken place through a parent satisfaction survey. The outcomes are still under analysis. In general, parents were very affirmative toward the program and liked the flexibility of the cash subsidy. They felt this was the only program that gave them a sense of empowerment.

Future directions: The FSSP has received good publicity, which will support its future expansion. Parents need to be involved at all levels of planning and development.

Lessons learned: In order for an effective family support system to develop a state must recognize that the family is a strong natural system. To respond to their needs is to respond to the community's needs. The informant felt it was best to start at the Governor's office. Perhaps that office more than any other agency can expedite a program.

Materials Reviewed

Copy of Senate File 2018: "Creating a Family Support Subsidy Program", 4-27-88.

Proceedings of the Comprehensive Planning Conference, September 1988, "Family Support Services for Iowans with Disabilities" by the Community Living Foundation for Iowans with Developmental Disabilities through funding provided by the Governor's Planning Council on Developmental Disabilities.

KANSAS

Name of program: Kansas does not have a separate family support program.

Nature of program: No legislation.

Date of Implementation: Not applicable.

Administering agency/contact person: Department Of Social And Rehabilitative Services, Division of Mental Health and Mental Retardation Services, Rich Schultz, Director of Community Mental Retardation Program, (913) 296-3561.

Type of program: Services are provided by the state's 27 Independent Community Mental Retardation Centers (ICMRC).

Number of eligible families served: not available.

Eligibility criteria: Individuals with mental retardation and developmental disabilities are eligible for services.

Services covered/allowable expenditures: Independent non profit agencies contract with the state to provide case management services, respite care, preschool services, and other rehabilitative/habilitative services.

Limit on Benefits to individual family: Services are based on need. Many of the ICMRC's have adopted a zero-reject policy.

Current Funding Level: Not available; budget is not itemized to identify family support services.

Background: Kansas does not have a formalized family support program. Rehabilitative, habilitative, and other social services are offered by the 27 ICMRC's.

Program structure: The ICMRC's are independently administered and services vary from region to region.

The centers' most active efforts are the preschool programs. In Kansas special education services are not mandated until the children become 5 yr. old. The ICMRC's are responsible for providing early intervention services. Eight hundred and twenty-one children were served in the preschool services. These services have a centered base and an in-home component.

These programs are well developed and provide comprehensive services. The informant felt that these programs will slowly be abolished as PL 99-457 is now being adopted and EI will now be under the auspices of the Department of Education.

Implementation Issues: The services provided by the ICMRC's are offered to individuals with developmental disabilities of all ages and income levels. Services are provided on a sliding fee scale. Consumers may not receive a broad range of services, but everyone gets at least minimal assistance.

In summary, Kansas' family support services may not be well-defined, but there is an effort to promote community life for individuals with developmental disabilities.

Medicaid Policy: Kansas has a Home and Community Service Model Waiver serving 422 individuals, 16 yr. or older with mental retardation. The waiver provides out-of-home placement services, in-home respite care, day habilitation, wellness monitoring (R.N. care), and over night monitoring (attendant care). The program's contact person is Becky Ross, Division of Mental Health and Mental Retardation Services, (913) 296-3561.

Related Efforts

The Kansas Department of Health and Environment. This Department has a prenatal screening and maternity care program aimed at preventing high risk pregnancies and improving outcomes. The program's contact person is Virginia Tucker, (913) 296-1300.

Children with Special Health Care Needs. This program, also administered by the Department of Health and Environment, provides diagnosis and treatment of specific conditions. The program's contact person is Cassie Lauver, (913) 296-1313.

As mentioned earlier, the Department of Health and Environment and the Department of Education will be taking over the responsibility for the EI (0-2 services) and preschool program (3-5 services). Currently these programs are provided by the ICMRC's. This change is receiving some criticism as it is felt that the centers are providing excellent services which should remain under their domain. The contact person for early childhood special education services is Alita Ash, (913) 296-6135.

Make A Difference Network. Kansas provides this information and referral number listing private and public services and state agencies: 1-800-332-6262.

Supported Family Living Pilot Projects run by the Department Of Social And Rehabilitative Services, Division of Mental Health and Mental Retardation Services, (Rich Schultz, Director of Community Mental Retardation Program, (913) 296-3561). This program provides a cash subsidy to the foster families of 12 children moved from a state hospitals into foster care. Child must be 16 years or younger and currently reside at one of the two state hospitals selected for the pilot project. Kansas has three state hospitals; two were chosen to participate in the pilot project.

The program provides for case management services, parent training, and respite care (provided at the institution), and the cash subsidy. Families may use the money in any way related to the care of the child. Benefits to Family is limited to $850 per month minus child's SSI. This program is currently funded at $75,000 for FY 1988.

The SFLPP is an offshoot of the state's therapeutic foster care program. There are two modifications to that program: 1) Parents of the child served by the SFLPP do not have to relinquish custody; and 2) SFLPP is only for children with mental retardation. This program's goals are to successfully place children out of the institution and identify the issues and the processes necessary to make this a permanent effort.

Twelve children were selected who were the least physically and behaviorally impaired and who had the greatest potential for a successful family placement. One child returned to the natural family; eleven were placed in foster care. The informant reported that most of the children who were placed in institutions came from dysfunctional families and returning children to that environment would not be feasible. Family involvement and visitations are encouraged, and the program is moving toward returning more children to their natural homes.

The Division did not have difficulty in recruiting families to provide care. Securing funding was an obstacle. In the future as the program expands, and children with more complex needs are discharged, locating qualified and willing families will become more difficult.

This project required the cooperation and collaboration of many departments. Foster family homes were licensed by the Department of Youth Services. Medicaid had to agree to allow the children to retain their medical benefits upon discharge from the hospital. And lastly, case management was provided by hospital staff who were less familiar with community resources.

This modest project is an attempt to return children to a more normal and integrated life. These twelve children attend public schools and participate in other community activities.

The future direction of this program will be to increase the number of children returning to community living, with a greater emphasis on reuniting them with their natural families, and developing family support services to prevent institutionalization in the first place.

Evaluation: Kansas has active parent involvement in several programs. There is strong representation in the Coordinating Council on Early Childhood Development concerning the 0-5 services. Additionally parents participate in the ad hoc, advisory, and steering committees of the Department of Social Rehabilitative Services. The Coordinating Council of Developmental Disabilities has a parent representative on all work groups. The University of Kansas Medical Center also has a parent advocacy group. These activities demonstrate Kansas' commitment to involving parents and using their input to shape policy.

Future Directions: The state of Kansas is slowly shifting from institutional care toward community-based care. They are moving closer to family support as well. Several small-scale pilot projects are underway. This allows the opportunity to examine several models and develop a creative system.

Lessons Learned: A family support system must avoid building a large bureaucracy. The state should keep administration to a minimum. Given that private vendors exist who are providing quality care, the state should support them rather than create its own system.

KENTUCKY

Name of Program: Kentucky does not have a Family Support Program as such. Services to individuals with MR/DD and their families are provided by the 14 independent Regional Boards.

Nature of Program: No legislation exists for family supports.

Date of Implementation: FY 1980

Administering Agency/Contact Person: Cabinet For Human Resources, Division of Mental Retardation, Charles Bratcher or Elaine Lake, (502) 564-7700.

Type of Program: Services are on a sliding fee scale.

Number of Families Served: The State does not have a figure that represents the number of families being served. The state reported a total of 3,541 family support *services* were delivered (this is a duplicated count).

Eligibility Criteria: All persons with mental retardation, mental illness, or developmental disabilities as defined by the federal guidelines are eligible for the 30 services offered through the local mental health centers.

Services Covered/Allowable Expenditures: Each regional program has a variety/combination of in-home supports, respite care, therapies, and so forth. There are 30 core services in all, the oldest of which is case management. These services are provided by the private non-profit regional boards.

Limit on Benefits to Individual Family: Services are determined based on the individual's needs.

Current Level of Funding: The FY 1988 budget for the "support services" was: Respite Care, $233,074; In-Home Supports, $889,134; and Special Services, $89,586. An additional Respite Care Program was funded by the federal government at $86,161. The total budget was $1,297955.

Background: Family supports do not exist as a separate program in the state of Kentucky. Kentucky is divided into 14 independent Regional Mental Health/Mental Retardation Boards. The Regional Boards offer a variety of services through the Department for Mental Health and Mental Retardation. Three services, 1) Respite Care, 2) In Home Supports, and 3) Special Services and Equipment, might be classified as "family support services". However, these services are not offered as a special package of services. Other services offered by the Regional Boards may include but are not limited to vocational training, speech, physical, and occupational therapies, and residential placement services. Waiting lists do exist for the various services and needs are prioritized through crisis prevention criteria.

The goals of the services that are provided by the Regional Boards are to "support and not supplant the family" and to prevent institutionalization.

Program Structure: The Regional Boards offer services to all individuals with mental retardation, mental illness or developmental disabilities. There is no restriction on age or income. Services are offered on a sliding fee scale.

The oldest service is case management which began in 1980. This service came about as a result of the push toward deinstitutionalization. The role of the case manager is help the individual/family identify and prioritize their needs. Each client receives an individual service plan.

Respite care is the second oldest "family support service" offered by the state. Several types of respite care exist. They include short term (more than one hour but less than 24 hours); extended care (more than 24 hours but less than 30 days. Both short term and extended care respite may be arranged either in or out of the home.

Implementation Issues: Kentucky has several limitations within their service delivery system. First, delivery of services varies according to the differences in priorities of the Regional Boards. Second, delivery of services also varies with respect to geographical location. For example, a family in a rural area may need assistance with transportation or travel expenses to attend a therapy or medical appointment, while a family in a metropolitan area may need assistance locating a service due to the density of resources already in place. Finally, because services are offered on a sliding fee scale, there is no defined limit to the amount of services an individual may receive. Limitations on the amount of services are more dependent on the availability of services than on the needs of the individual.

In summary, the Kentucky program might be described as individual/center driven versus family/community driven. Services lack continuity and are fragmented throughout the state.

Medicaid Policy: Kentucky has had a Title IXX Waiver since 1982; "Alternative Intermediate Services" for persons with mental retardation. The program offers six services to individuals in community settings: 1) case management, 2) in-home supports, 3) residential services, 4) habilitation, 5) adult day habilitation, and 6) respite care.
The contact person for the Medicaid Waiver is Bill Wilson, (502) 564-7700.

Related Efforts

Perhaps the most coordinated system of services offered to families in the state of Kentucky are the educational/early intervention services for young children.

The Dept. of Mental Health and Mental Retardation. This is the lead agency for P.L. 99-457. The main focus of the program is to reduce family stress by addressing a variety of needs that enhance child development. The Department also has an active child-find system. The contact person for this program is Jim Henson, (502) 564-7700.

Department of Education. The 0-2 program works closely with this Department, which is responsible for the 3-5 yr old special education services. The contact person for the Dept. of Education is Maggie Chiara (502) 564-4970.

Department of Social Services. Other agencies involved in family services are administered by this Department. The contact person is Nancy Rawlings, Director, or Betty Triplett, (502) 564-6852.

The Department of Health/Maternal and Child Health. The contact person for this Department is Dr. Pat Nichol, (502) 564-4830.

Evaluation: The weaknesses of the "family support program" in Kentucky have been addressed under Implementation Issues. Professionals remain committed to a traditional, out-dated service base. Programs are geared for serving large numbers of clients rather than for developing individualized programs which serve smaller numbers.

Kentucky's strengths appear to be in the child service sector. As mentioned earlier, these services are better coordinated and more readily available.

Future Directions: Currently the state of Kentucky has no plans to develop a family support policy. Families are more involved now then ever before; they are represented on every committee and are gaining more confidence. Hopefully this will lead to an improvement in the development of services and to an increase in funding.

Lessons Learned: It is important to maintain a developmental model rather than a medical model when developing a service system geared for persons with mental retardation. It is also important that services be developed around the needs of the individuals.

Material Reviewed

A listing of the 14 Regional Boards, the directors, addresses, and phone numbers.

A listing of the state Departments, directors, and phone numbers.

LOUISIANA

Name of Program: 1) Respite Services
2) In-Home and Family Support
3) Pilot Cash Assistance and Family Support Programs
4) A newly legislated project to develop and implement a Community and Family Support System.

Nature of Program: 1) Respite: ongoing, state funded service; 2) In Home and Family Support : ongoing, state program; 3) Cash Assistance and Family Support: two pilot projects; and 4) Legislatively mandated planning and implementation program to establish family support services.

Date of Implementation: 1) In 1979 statewide respite care programs were implemented using Title XX funds; 2) In Home and Family Support also began in 1984; 3) The pilot cash assistance and family support programs both began in 1989; and 4) Legislation putting in place a planning and implementation process for a statewide family support system was passed in 1989.

Administering Agency/Contact Person: For: 1) Respite Services: Keyth DeVillier, Office of Community Services, Department of Social Services, PO Box 44367, Baton Rouge, La. 70804, (504) 342-2272; 2) In Home and Family Support: Alma Stewart, Office of Human Services, Division of Mental Retardation, P.O. Box 3117, Bin #2, Baton Rouge, La. 70821, (504) 342-0095; and 3) Family Support Planning Project and Pilot Cash Assistance and Family Support Programs: Sandee Winchell, Louisiana State Planning Council on Developmental Disabilities, P.O. Box 3455, Baton Rouge, La 70821-3455, (504) 342-0437.

Type of Program: 1) In home and center-based respite services are primarily provided in the population centers of each region of the state; 2) Cash reimbursements to families to offset the cost of services and goods needed to care for a family member with disabilities; 3) Pilot cash assistance and family support projects in the northwest and southwest sections of the state; and 4) a statewide planning effort to design and implement family support services for the state of Louisiana.

Number of Families Served: 1) Respite care was provided to 941 individuals who receive 201,319 hours of respite care for FY 1988/89; 2) In Home and Family Support served approximately 64 families in the past fiscal year; with increased funding the number of families should be approximately doubled in FY 1989/90; and 3) Cash Assistance and Family Support Projects will assist 30 families, 15 in each participating region.

Eligibility Criteria: 1) Respite services: An individual must have a chronic physically or mentally disabling condition, that is not primarily a result of the aging process, and is likely to continue indefinitely and results in limitation in three of the following major life activities: self care, receptive and expressive language, learning, mobility, self direction, and sufficiency; 2) In Home Family Support: Individual must have mental retardation or a related condition; there is no income or age limitation; however, the majority of families in this program have an income below $25,000; 3) Cash Assistance and Family Support: Families must be residents of the pilot areas and have a severely developmentally disabled child (under the age of 18) living at home.

Services Covered/Allowable Expenditures: 1) Respite: In- and out-of-home care; 2) In-Home Family Support: Reimbursement for needed services and goods, quite flexible about what dollars are spent for; 3) Cash Assistance and Family Support: Families are provided with $250 per month; additional services are provided on a sliding fee scale. The program is very flexible, services and cash assistance are provided according to individual family need.

Limit on Benefits to Individual Families: 1) Respite Care: Limited to 720 hours in a six month period; 2) In Home and Family Support: Expenditures to families vary according to family circumstances; 3) Pilot Cash Assistance and Family Support Programs: $250 per month is allocated for each participating family; as needed, additional services are provided on a sliding fee scale.

Current Funding Level: 1) Respite Care: $1.27 million; 2) In Home Family Support: $334,378 (program allocations have increased steadily over the past three years: $45,000 FY 86/87, $147,000 FY 87/88); 3) Cash Assistance $100,000 for each of the two pilot programs.

Background: Louisiana has the highest per capita institutional population in the country. Over 700 Louisiana children (under the age of 21) reside in public institutions. The Office of Mental Retardation and Developmental Disabilities (recently merged with the departments of Mental Health and Drug and Alcohol Abuse and renamed the Office of Human Services) has had an historical bias towards institutional placements. Many of the community services, including respite care, that are in place came about as the result of the Gary W. class action law suit (a suit against the state concerning the care and treatment of Louisiana children placed in Texas institutions). While in the past, very few services have been available to families caring for a person with disabilities; this is slowly beginning to change.

Program Structure: 1) Respite Care: The Department of Social Services contracts with local private providers, primarily Associations for Retarded Citizens, to operate respite services. The goals of the program are to avert institutionalization, assist families during crisis situations, and to provide relief to care givers. Both in and out of home care is available. Quality assurance is provided through licensing reviews as well as annual programmatic monitoring by the Department of Social Services. Providers, as part of their contract, are required to conduct internal monitoring and assess client satisfaction of services. Because of limited funding, respite services are not widely advertised.

2) In-Home and Family Support: This program is funded by the Office of Human Services (formerly Office of Mental Retardation and Developmental Disabilities) and administered through case management in the Division's eight regional offices. Families in the program are actively involved in deciding what services and resources family support will fund. Funding for this program was substantially increased during the last legislative session.

3) Cash Assistance and Family Support: The Developmental Disabilities Council has recently funded two pilot programs, Project Home in Lake Charles and Families Plus in Shreveport. The programs are operated by independent private non-profit case management organizations.

Implementation Issues: 1) Respite Care: These services were originally Title XX funded and only available to lower and middle income families. Funding for respite services has shifted back and forth between federal and state general fund dollars. For the past and current fiscal years respite care has been funded out of the state general fund. The Department of Social Services' primary responsibilities are foster care and child welfare services which are mandated by law. Funding for respite care has not been increased for several years. A recently contemplated 50% reduction of the respite budget was not implemented, and the funding status quo has been maintained. Because of an uncertain state budget and delay in appropriations, several providers did not fund respite care for Louisiana families during July.

Local Associations for Retarded Citizens have traditionally been the contractors for respite services; individuals with mental retardation and their families have been the primary beneficiaries of respite services; 66% of all respite care recipients were persons with mental retardation. Families whose family member has a disability other than mental retardation have not received the same level of respite services; for example, 3% were persons with autism and only 1% of the respite recipients are persons with emotional disturbances. Respite is primarily available in the population centers of the state's regions; residents of rural parishes have had few or no resources for respite care. Due to limited funding there has not been an active outreach effort to inform families about the service. Even without advertising the program, the state has a lengthy list of 300 unmet requests for respite care. In the past year there have been over 15,981 hours of respite requested that the state could not provide.

2) In-Home and Family Support: Louisiana's service system has had difficulty in providing timely help to families. This program is administered by case managers whose have had to concentrate primarily only on crisis situtations. Large case loads (approximately 45) and other structural issues have made it difficult for the case management system to respond adequately to the complex and sensitive problems families present. Assistance to families is in the form of reimbursement for services. For many families the need to provide up front cash for services presents a real hardship. While the program has problems which need to be ironed out, the state's commitment to families is increasing. In each of the past two years funding for In-Home and Family Support services has doubled.

3) Cash Assistance: Too soon to say

Medicaid Policy: Louisiana has requested a Home and Community Based Care Waiver which, if granted, would be used to help cover the cost of personal assistance and respite care services. Case management is currently being expanded under the state plan. Information about Medicaid may be obtained from Mr. Jerry Vincent, Office of Human Services, P.O. Box 3117, Bin #2, Baton Rouge, La. 70821 (504) 342-0095.

Related Efforts

Office of Public Health. Through its Handicapped Children's Programs, this office operates two pilot projects in New Orleans and Lake Charles for children with physical disabilities and their families. Each program has a full-time social worker and a half time parent support person. For more information contact: Stella Guidroz, Office of Public Health, P.O. Box 60630, New Orleans, La. (504) 568-5005.

Children's Hospital in New Orleans. Using federal funds, this hospital runs two programs that serve sick children and their families. **The Ventilator Assistance Program** uses Medicaid dollars to serve about 70 children and their families, providing case management and other assistance to enable children using ventilators to return to or remain at home. **The Chronic Illness Program**, funded through a SPRANS grant from the Bureau of Maternal and Child Health, works closely with school districts to help support sick children at home and in their community schools. This program has provided a variety of services to over 500 children and their families and has been extremely successful. However, federal funding for the program will soon be running out, and the continuation of the project is in jeopardy. Information about these programs can be obtained from the programs' Medical

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Director, Joanne Gates, Childrens' Hospital, 200 Henry Clay Avenue, New Orleans, La. 70118, (504) 899-9511.

Children and Adolescents Social Services Program (CASSP). This program, administered through the state's Department's of Mental Health and Education and the Juvenile Justice system, examines how services can be better coordinated for emotionally disturbed children and their families. Information can be obtained from: Ron Boudreaux, CASSP Project Director, Office of Mental Health, P.O. Box 4049, Baton Rouge, La. 70821, (504) 342-2534.

Evaluation: In the past few years Louisiana has made significant changes in how it regards and treats families who have a child with a disbaility. While institutional enrollment is still unacceptably high, the state is beginning to offer families other alternatives. These alternatives, while representing an important move in the right direction, are only available to a limited number of the state's residents. The services offered through the respite care, family support, and cash assistance programs need to be evaluated, refined where needed, and extended to families across the state.

Future Directions: On June 29, 1989, Louisiana's Governor Roemer signed into law House Bill 1380, a piece of legislation which has the potential to improve significantly the quality of life for families caring for a family member with developmental disabilities. The bill calls for the "development of a Community and Family Support System plan by the Louisiana State Planning Council on Developmental Disabilities by August 1, 1990 and implementation of the plan by the Department of Health and Hospitals with the cooperation of the Department of Social Services by July 1, 1991." The bill includes strong language, establishing the guiding principles for the state's emerging family support system. To assist in the development of a family support plan, Louisiana will be receiving technical assistance from Human Services Research Institute and United Cerebral Palsy as part of a Federal grant to educate policy makers on family support issues.

Lessons Learned: Louisiana's Planning Council Director advises states interested in developing family support to involve families intimately, from the beginning, in planning and lobbying efforts. To meet individual family needs, family support programs need to be kept as flexible as possible.

Materials Reviewed

HB 1380, Family Support Legislation.

MAINE

Name of Program: 1) Respite Care, and 2) Child Development Services

Nature of Program: Ongoing statewide services, Legislation establishing Bureau of Children with Special needs gives it a clear family support mission.

Date of Implementation: 1) Respite Care began in 1982 2) Child Development Services began in 1973.

Administering Agency/Contact Person: 1) Susan Failing, Bureau of Children with Special Needs, The Elizabeth Levinson Center, 159 Hogan Road, Bangor, ME 04401, 1-800-227-7706 (in Maine) for out of state callers, (207) 941-4400; 2) Linda Pierce, Bureau of Mental Retardation, State House Station 40, Augusta, ME 04333, (207) 289-4242; and 3) Dr. Robert Durgan, Bureau Chief, Bureau of Children with Special Needs, State House Station 40, Augusta, ME 04333, (207) 289-4250.

Type of Program: 1) Respite Care: temporary in or out of home care; 2) Child Development Services: early intervention services.

Number of Families Served: 1) Respite Care: Currently, 450 families receive respite through the Bureau of Children with Special Needs; 2) Respite Care: In FY 1988/89 between 900-1,200 families received respite through the Bureau of Mental Retardation; and 3) Child Development Services: 1,303 children were served in FY 1988/89.

Eligibility Criteria: 1) Respite Care: birth to twenty who have special needs and who are not eligible for services from other state agencies; 2) Respite Care: persons with mental retardation or autism older than five years of age; 2) Child Development Services: children birth to five years of age with a developmental delay or at risk of a developmental delay.

Services Covered/Allowable Expenditures: 1) Respite Care: In- or out-of-home care; 2) Child Development Services: therapies, case management, family support, screening, evaluation, play groups, and home teaching services.

Limit on Benefits to Individual Families: 1) Respite Care: provided by the Bureau of Children with Special Needs will pay for a maximum of 24 days of respite a year. Reimbursement rate depends on the complexity of care: Level I $720 per year, Level II $960, and Level III $1,200. 2) The Bureau of Mental Retardation negotiates with individual providers to establish a respite care rate, there is some regional discretion on the number of respite days allocated per family.

Current Funding Level: 1) Respite Care: the Bureau of Children with Special Needs has a respite budget of approximately $1 million dollars (this is an increase of $375,000 over last year's allocation); 2) Respite Care: the Bureau of Mental Retardation has a respite budget of approximately $500,000; 3) Child Development Services: $1,105,701 in FY 1988/89.

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Background: In 1985 the Bureau of Children with Special Needs was created; this Bureau succeeded the Office of Children's Services. Located within the Department of Mental Health and Mental Retardation, this new Bureau has equivalent status with the Department's Bureau of Mental Health and Bureau of Mental Retardation. Financial and personnel resources relating to children were reassigned to the new Bureau. The Bureau has sought to expand and improve services to Maine children who have special needs.

Program Structure: Services are provided by the Bureau of Children with Special Needs within the following policy mandates: 1) to strengthen the capacity of families as primary caregivers for children in need of treatment; 2) to facilitate the development of a complete and integrated statewide system of services to children in need of treatment and their families; and 3) to provide in-home, community-based, and family oriented services.

The Bureau provides services both through its own employees and through contracts with provider agencies. In the majority of instances, the Bureau's dollars are combined with those of other child-oriented programs or agencies: public schools, Department of Corrections, Department of Educational and Cultural Services, and the Developmental Disabilities Planning Council. As a result, a major emphasis of the Bureau has been collaboration with other agencies through the Interdepartmental Council to strengthen Maine's services to children and families.

1) Respite Care: Since October 1988 Respite Care has been a state funded program through the Bureau of Children with Special Needs. Parents were actively involved on the Respite Care Advisory Board that set up the program. The Bureau has an 800 number families can call to get information, referral, and coordination of respite services. Respite Care Coordinators in the Bureau's Northern and Southern offices assist families in finding and arranging respite care. Respite care can be provided by either a caregiver licensed by the Bureau or by a provider of the families' choosing. For licensed providers, the Bureau pays for liability insurance. The Bureau in conjunction with the Bangor and Portland Red Cross Chapters has developed a program to train and certify respite care providers; 200 providers have been trained statewide. The program is expanding to include training on providing respite care for children with autism. On an individual basis parents evaluate their respite care providers.

2) Child Development Services: are provided directly by the Bureau through six regional offices located in South Portland, Lewiston, Augusta, Bath, Bangor, and Presque Isle. Case management services and family support are components of early intervention.

Implementation Issues: The respite care program administered by the Bureau of Children with Special Needs has been highly successful. From the first to the second year of the program participation has increased 400%. The program has been widely advertised. Allocations for respite were increased in the last legislative session; the program expects in the course of the biennium to serve twice as many families as its current enrollment. Currently the program has no waiting list.

There is no fee for respite provided through the Bureau of Children with Special Needs. The Bureau of Mental Retardation requests, but does not demand, a contribution for respite provided through its offices.

Maine, through the Interdepartmental Council and in particular through the Children and Policy Committee, has made a concerted effort to coordinate its services to children and families. At the state level this interagency coordination has meant that no major children's services are planned, funded, or administered in isolation.

Medicaid Policy: Maine currently has two requests for Medicaid waivers pending. Information about Medicaid can be obtained from: Dr. Robert Durgan, Director, Bureau of Children's with Special Needs, State House Station 40, Augusta, ME 04333, (207) 289-4250.

Related Efforts

The Bureau of Children with Special Needs. This bureau has several additional programs that provide support to families caring for a child with a disability:

The Home-Based Family Services. This program provides both intense short term (maximum three months) and long term (1-2 years) family intervention to families who have a child with severe, chronic emotional, and behavioral problems. The goal of these services is to prevent the potential removal of a child from the home or to promote reunification of a child with his or her family.

Specialized Home- and School-Based Services. These services, for children and youth who have autism, are available in five of the Bureau's six regions. They are delivered by child development workers who act as a liaisons between home, school, and community. A family co-therapy model is utilized to promote the use of consistent behavioral strategies for the child.

Parent to Parent and Parent Support Groups. These groups provide peer support, information and education, and advocacy for parents of children and adolescents who have severe emotional disturbance. The Bureau provides staffing to assist in the development and maintenance of these groups.

Information about services provided by the Bureau of Children with Special Needs can be obtained from: Dr. Robert Durgan, Bureau Chief, Bureau of Children with Special Needs, State House Station 40, Augusta, ME 04333, (207) 289-4250.

Maine's Bureau of Mental Retardation. This state office offers training opportunities for families and has a small (current enrollment is 47 young adults) Transitional Services program. The program, also known as the voucher system, offers a method of funding innovative services which would otherwise not be available or not reimbursable under existing systems. To be eligible for the program an individual must be: a) between the ages of 20-26 years; b) living at home or in unsubsidized foster care and not receiving any

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day program or receiving inappropriate day program services; c) must be unable to obtain needed services from any other sources; and d) must be a client of the Bureau of Mental Retardation. Services funded may include: evaluation, job placement, counseling and follow-up, job coaching, supported employment, vocational training, day habilitation, transportation, respite, recreational and leisure activities, and post-secondary education. For additional information contact: Linda Pierce, Field Operations Manager, Bureau of Mental Retardation, State House Station 40, Augusta, ME 04333, (207) 289-4242.

Maine's Bureau of Mental Health. This bureau has recently hired a Family Support Coordinator to act as a liaison between the service system and families. The Coordinator currently has on-going contact with approximately 24 families. This Bureau also provides $100,000 to support Maine's Alliance for the Mentally Ill and helps to fund 10 local alliance groups. The Bureau of Mental Health has allocated resources to train 50 Maine families in the area of crisis intervention. Respite care has been identified as a top service priority by the Bureau; funds to establish respite care will be sought in coming legislative sessions. For additional information contact: Jay Harper, Bureau Chief, Bureau of Mental Health, State House Station 40, Augusta, ME 04333, (207) 289-4200.

Maine's Bureau of Child and Family Services. This agency is responsible, among other things, for child abuse prevention, protective services, and state welfare programs. Through a Dependent Care Grant, this Bureau subsidizes child care. The Bureau's Income Maintenance program offers home-based family support and counseling to AFDC (Aid to Families with Dependent Children) recipients, 70-75% of the state's AFDC recipients take advantage of this service. For additional information contact: Peter Walsh, Bureau Chief, Bureau of Child and Family Services, State House Station 11, (207) 289-5060.

PL 99-457. Through implementation of this legislature, Maine provides coordination of preschool services for children with disabilities and limited direct services to families. Information about these activities can be obtained from: Susan Mackey-Andrews, (207) 289-3272.

Northeast United Cerebral Palsy. With funding from the Bureau of Children with Special Needs and United Way, NUCP operates a Respitality Program. This program which originated in Bangor has recently received funding to operate statewide. Respitality provides Maine families who have a family member with a disability the opportunity to have a free evening or weekend in a Maine motel or hotel. Hotels donate the use of rooms for the program; local restaurants donate meals; and donations of entertainment (theater, music) are currently being investigated. For more information contact: Ruth Shook, Executive Director, Northeast United Cerebral Palsy, 103 Texas Avenue, Bangor, ME 04401, (207) 941-2885.

Maine Parent Federation. Maine has a number of local family support and advocacy groups; many of these are represented in this statewide coalition, providing information and referral, parent training, support, and legislative advocacy. For additional information contact: Deborah Guimont, Executive

Director, Maine Parent Federation, 1-800-325-0220 (out of state call, (207) 582-2504.)

Evaluation: At the state agency level Maine has developed strong policies in support of families. The local service delivery system is beginning to reflect the change in emphasis from isolated individual treatment to services which support the entire family and enhance their caregiving capabilities. The development of home based services for families who have children with emotional disturbance or autism, child development services for families who have a young child with developmental delays, and expanded respite care are examples of increased family support.

The state's commitment to interagency collaboration and coordination at the state level is laudatory. However, Maine has not yet developed a mechanism for resolution of difficult cases at the local level.

As is true nationally, Maine services are not funded adequately to meet existing individual or family needs. However, with a well organized and persistent grass-roots lobbying effort by families, providers, and advocates this may begin to change. Maine's state agencies are beginning to embrace the values of community integration and family support. There needs to be a concerted effort to plan and coordinate family support at all levels of the service system. Families must be included as true, not token, partners in this effort. With additional money and the inclusion of families in designing services, the state may be in a position to establish a family support system.

Future Directions: Services to children and families have been the subject of much scrutiny by several Maine agencies. In the past year the Bureau of Children with Special Needs, the Bureau of Mental Retardation, and the Developmental Disabilities Council all issued major planning documents.

Each of these emphasized the need to recognize and support the care provided by families to their disabled family members. Recommendations in these reports all call for a substantially increased state commitment both in policy and dollars to families caring for persons with disabilities.

Among specific recommendations are: 1) the need for responsive information and referral services; 2) additional respite and child care; 3) widely available case management services; 4) ways to connect with other families who have special needs; 5) adequate, affordable health coverage; 6) availability of family counseling; 7) future planning services; and 8) education and training for families. The reports stressed the importance of promoting independence and community integration for individuals with disabilities. They also stated families have a right to full partnership in deciding what resources and services will best meet their needs.

To move Maine in the direction of adequately supporting its families, the Developmental Disabilities Council is organizing a statewide grass-roots lobbying coalition. This coalition, comprising 75-100 advocacy and parent groups, was successful in the last session in increasing funding for respite care. They will be returning to the Maine legislature in January 1991 to ask for a strong state policy supporting families and for substantially increased appropriations for services directed to families. The Developmental Disabilities Council has recently been awarded a Technical Assistance grant from Human Services Research Institute to assist them in this effort.

Lessons Learned: To establish family support that is available and responsive to all families who have a family member with a disability, the Developmental Disabilities Council emphasizes the need to build a strong grass-roots coalition which crosses age and disability lines. Too often disability special interest groups are seen as fighting each other rather than working together. In pursuing a legislative agenda, it is important to realize that tenacity is a key to success. A strong showing at one hearing won't do it; families must make the commitment in time and energy for the long haul.

Materials Reviewed

Bureau of Children with Special Needs, Biennial Plan 1989-1990, State of Maine Department of Mental Health and Mental Retardation, January 1989.

Caring for Families for Care, The Report of the Family Contribution Study, Maine Planning and Advisory Council on Developmental Disabilities, Peter Stowell, Executive Director, L. Jean Price, Study Consultant, May 1989.

Dispatch, Newsletter of the Maine Developmental Disabilities Council, May 1989.

Report to the 114 Legislative Joint Standing Committee on Human Resources, prepared by the Bureau of Mental Retardation, January 1989.

Maine Laws, Chapter 6, Children with Special Needs.

A Plan for People, developed by the Long Range Planning Task Force to Meet the Long Range Needs and Interests of Maine Citizens with Mental Retardation or Autism, supported by the Maine Bureau of Mental Retardation, December, 1988.

Bureau of Mental Retardation Pilot Program for Transitional Services, Chapter 7, effective September 6, 1988.

MARYLAND

Name of Program: Family and Individual Support Program

Nature of Program: Legislative mandate

Date of Implementation: 1982

Administering Agency/Contact Person: Developmental Disabilities Administration Contact: Hal Franklin 301-225-5583.

Type of Program: Services

Number of Families Served: 1,500 project wide. 300-500 additional families receiving short-term service.

Eligibility Criteria: Eligibility criteria have been loose. Families must be considered "at risk" and what is defined as "at risk" is often determined by an area agency. What might be "at risk" for out-of-home placement in one area is not so in another. Income, for example, varies from city to small town. Income criteria also vary according to area. Few families are denied services because they are over the state's income criteria.

Services Covered/Allowable Expenditures: The program covers respite services, behavior management, before and after school transportation for recreation, the purchase of equipment, medical supplies, and some therapies that insurance does not cover. It is fairly open-ended.

Current Funding Level: approximately $4,000,000.

Background: In 1982, the Developmental Disabilities Council in the State of Maryland put out requests for proposals for family support programs. Three were grants and were funded to serve five agencies; the first year, a pilot was funded by the Developmental Disabilities Council. Children under the age of 22 years living at home or placed outside the home but whose family wanted them to return were the group that were targeted for service. The first-year pilot was used to gather data on what types of services were needed and their approximate cost.

In 1983, a bill was passed which supported family supports in the state and the budget for the program was increased.

Family supports in Maryland are similar statewide and modeled after the pilot project. The original sites served as models for programs initiated in other areas of the state. Any agency that seeks funds is eligible for family support funds. Although more then 35 agencies are presently receiving funds, many only provide services to adults.

All other service provisions are exhausted before family supports funds are looked at as an alternative.

Program Structure: The main goals of the Maryland Family and Individual Support Program are to maintain and support families in the community. The focus of the program are those children or families that are at risk of out-of-home placement, and families of children labelled multiply handicapped. This focus has now been expanded to include adults.

A referral is taken by a local agency and a home visit is initiated by a coordinator who then establishes contact with the family. At this time, what the family needs and what the agency can provide is identified. A service plan is developed almost immediately and service provisions begin.

Services can come from within or from outside the agency. The priority is to determine what will make a difference for the family and then to tap into other available resources, whether they be food stamps, Medicaid or other state or federal programs. Family support funds are then used as a resource of last resort.

Quality control issues are handled in several ways. On an agency level, a supervisor reviews all the families of each coordinator. Under new regulations, regions will be responsible for reviewing all service plans. On an annual basis, an evaluation is sent out to families who offer input on their feelings about the services they receive.

Implementation Issues: Criteria related to eligibility issues have been loose and basically determined by the agency receiving the funds. Much emphasis has been placed on developing criteria for defining "at risk" by the individuals screening the family. These criteria vary for each agency. Some agencies have a sliding fee scale or co-payment system, which is determined by the individual agencies. Families have a right to appeal decisions. But even with these arbitrary criteria, less than 5% of families applying for services have been turned away. Up to a year and a half ago, there was no waiting list for services. One now exists, but the number of families on it is unknown.

There has been extensive interagency cooperation in the program. If what is needed cannot be provided by the agency working with the family, support is available from other agencies. One agency might be able to support 80% of a needed service and request and additional 20% support from another agency. This can occur because the funding is flexible and not necessarily confined to services within one agency.

Medicaid Policy: Medicaid is not used specifically for family support services. It is accessed if appropriate for those families qualified for Medicaid services. For more information, contact: Hall Franklin 301-225-5583.

Related Efforts: None identified

Evaluation: The Maryland family support program offers a good deal of flexibility to families and to agencies that receive family support funds.

Criteria of eligibility are somewhat arbitrary and the factors designating "at risk" appear subjective.

Funding remains an issue; services are being funded at virtually the same level as two years ago, which limits services in relation to the increasing demand.

The program offers individual agencies the ability to expand their Family Support Programs.

The state seems to have a strong commitment to family supports.

Future Directions: There are proposed new regulations which will create some consistency in program operations.

There has been and must continue to be philosophical changes within agencies related to including families centrally in the process of determining what services they need. This is happening but to a limited degree.

There must be an increase in funds to avoid limiting quality services.

Lessons Learned: Flexibility has proved to be a big aspect of the Maryland program. This, as well as the documentation gathered in the pilot stages, have guided the provision of services to the present stage. This data was also vital in winning the passage of supporting legislation.

Materials Reviewed: None received

MASSACHUSETTS

Name of Program: Family Supports

Nature of Program: No legislation for family supports; Respite care was legislated eight years ago.

Date of Implementation: FY 1984

Administering Agency/Contact Person: Department of Mental Retardation (DMR), Casey Seaman, Director, Office of Family Support, (617) 727-5608.

Type of Program: Direct services are contracted by local service centers.

Number of Eligible Families Served: 3000 families received family support services; 10,000 families received respite care in the past fiscal year.

Eligibility Criteria: Any resident of the state who has mental retardation and lives with his/her natural/adoptive family is eligible for services. There are no limits based on age or income. Respite care also includes individuals with developmental disabilities.

Services Covered/Allowable Expenditures: Families are free to choose from any number of services related to the care of their family member. Services such as transportation, adaptive equipment, homemaker services, recreation, respite care, therapies, and counseling are some of the permissible services.

Limit on Benefits to Individual Family: Family support services are based on the need of the individual families. Respite care is limited to 100 hours every six months. Waivers are available to those families needing more than this amount.

Current Funding Level: Family support is funded at $3.5 million for FY 1989. Respite care is funded at $15 million; $7.5 million was money transferred from the Department of Social Services, which previously administered the program.

Background: Family support services became available to families caring for dependents with mental retardation four years ago. Prior to this time respite care was the major family support service available. Respite care is the service that is most readily available.

The goal of family support programs is to maintain the individual with mental retardation in his/her natural home. Four principles have been adopted to lead the program: 1) the program must be family driven; 2) services must be easily accessible; 3) services must be flexible to meet the individual needs of the families; and, 4) services must be coordinated and integrated with community resources.

Respite care is provided to individuals with developmental disabilities as well as to individuals with mental retardation. Prior to 1988, respite care was administered by the Department of Social Services. A separate respite care program administered by the DMR existed for persons with mental retardation. The state decided to move the DSS program over to the DMR program and have one department in charge of the administration. DMR agreed to continue to serve the clients with developmental disabilities. However these clients are not eligible for the other family support services unless they also have a diagnosis of mental retardation.

The goals of the respite care program are: 1) to support families in their caregiving tasks; 2) to enhance families' ability to care for their dependent; and, 3) to prevent out-of-home placement.

Program Structure: Family support services are provided by the 26 local service centers through out the state. To be eligible for services a person must have a diagnosis of mental retardation. This criterion is less strictly applied to younger children where a diagnosis of mental retardation has not yet been confirmed. To receive respite care a person must have a developmental disability.

The family support program is very flexible and responsive to the individual needs of the families. Families are in control and the program tries to embody the ideal of family empowerment.

The family support dollars have been able to supplement already existing services. This adds to the alternatives and choices families have when selecting the programs they need.

Implementation Issues: State funding for DMR's Family Support Services is uneven across the state, which affects the availability of services from region to region. Some providers are very flexible while others limit the amount of services a family can receive. Respite care has a waiting list of 1600 individuals and families receive service on a first come-first serve basis.

In general, the Family Support Program is an adequate and improving network of services for persons with mental retardation. The local programs are working to encourage a more efficient use of generic services and promote community integration.

Medicaid Policy: The Home Care for Disabled Children (HCDC) Program is a Medicaid funded program which serves children who are severely disabled and living at home, who qualify for Medicaid services regardless of parent's income status. The contact person for this program is Ruth McKinnon, (617) 348-5510.

Additionally, the Omnibus Waiver for persons with mental retardation has been in place for four years. Medicaid has served over 700 clients under this program which reimburses for community based services.

Related efforts

The Department of Public Health. This is the lead agency for implementing PL 99-457 part H. Early Intervention services are delivered by local providers to children aged birth-3. The state has a well-developed system in place. The contact person for this program is Ron Benham (617) 727-5090.

Evaluation: Massachusetts has a strong family support program. Parents have an active role in the planning and delivery of services through DMR's advisory committee and family support steering committee. Quality assurance and monitoring of providers of care take place at the local service centers.

A statewide interagency coalition on family supports sponsored several conferences and will be holding a Boston area conference targeted to urban families. Additionally, the Commissioner of Mental Retardation has conducted annual public meetings for the past three years and has met with over 500 families. The Commissioner also publishes a newsletter (with a mailing list of 2500) for families on a quarterly basis. DMR has also developed and distributed a resource guide for families to help them navigate the human service system in the state.

Participants at a statewide conference last year developed a list of seven recommendations to improve the respite care program. 1) expand reimbursement for respite care; 2) increase family access to quality programs and trained workers; 3) conduct special training and behavior management classes for workers and families; 4) promote and increase mainstreaming and integration of individuals with disabilities by using generic/community services whenever possible; 5) be sensitive to minority and cultural diversity; 6) recognize needs of other family members; and 7) emphasize collaborative effort between state funding sources and private sector resources to provide financial support necessary to implement recommendations.

Future Directions: The DD Council will assist with expansion of family support in Massachusetts by funding a cash subsidy pilot program in the fall of 1989 for 30 families.

Lessons Learned: The state and its designated mental retardation agency needs to listen directly to families in order to develop and provide a sound and meaningful family support system.

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The state needs to move toward developing community acceptance of individuals with mental retardation and their special needs and move away from reliance on a segregated service system.

Materials Reviewed

Family Services and Family Support: Current Approaches and Future Challenges, prepared by the Massachusetts Developmental Disabilities Council, August, 1988, (report discussing service delivery, family needs, and future directions).

Massachusetts Department of Mental Retardation: Family Support Newsletter, Sept. 1989 (updates families on relevant state events, article on sibling relationships, and upcoming events).

A Guide to Family Services, Commonwealth of Massachusetts, Department of Mental Retardation, May 1, 1989 (a state directory of human and health services for families with a useful bibliography).

MICHIGAN

Name of Program: Family Support Services Program (FSSP)

Nature of Program: Legislated in Public Acts of 1983, Act 249; amended in Public Acts of 1984, Act 358.

Date of Implementation: FY 1983

Administering Agency/Contact Person: Department of Mental Health, Susan Arneaud, Director of Family Support Services Program, (517) 335-4070.

Type of Program: The Michigan FSSP offers a comprehensive array of services to the families of children with severe impairments that may include case management services, respite care, parent training and education, counseling, support groups, crisis intervention, and a cash subsidy.

Number of Families Served: 3,300 families are receiving the cash subsidy. No clear figure available on regional family support service usage.

Eligibility Criteria: The Michigan FSSP serves persons with developmental disability based on need determined by the Community Mental Health Boards. The cash subsidy is directed toward families with children between the ages of 0-18. They must be evaluated by the public school district multi-disciplinary team and require services for children who are Severely Mentally Impaired (SMI), Severely Multiply Impaired (SXI), or Autistic Impaired (AI). The child must live at home with the natural or adoptive parent(s). And the family's taxable income cannot exceed $60,000.

Services Covered/Allowable Expenditures: One of the services of the FSSP is a direct cash subsidy to the families. Although parents must verify that the subsidy was used for the special needs of the family, there are no restrictions on how the money may be spent. In addition, the county mental health centers offer the host of family support services mentioned above.

Limit on Benefits to Individual Family: Each eligible family receives $256 per month. Services determined individually at regional center.

Current Funding Level: The Family Support Program's budget for FY 1988 was $14,679,251. This figure represents $9 million for the family support subsidy and $5 million for the other family support services.

Background: The family support subsidy program of Michigan, established in 1983, is one of the earliest and most progressive programs in the nation. The department's philosophy is that "A well-planned family support service delivery system reduces the need for crisis intervention and out-of-home placement while enhancing opportunities for families to participate more fully in community activities."

The goals of the program are: To prevent or delay out-of-home placements of children with educational classifications of Severely Mentally Impaired, Severely Multiply Impaired, or Autistic Impaired; and to facilitate the reunion of families whose children are in out-of-home placements.

In 1980, the program started as a pilot project available in several counties and soon moved to a state wide effort.

Program Structure: One of the principle components of the Michigan FSSP is a cash subsidy. The monthly stipend allows families maximum flexibility and control to meet their needs in caring for a disabled child. While families must verify that the subsidy was used for the special needs of the family there are no restrictions on expenditures. This feature empowers families to decide their priorities rather than the program delivering a set of prescribed services. While the cash subsidy is a unique feature of the Michigan FSSP, it occurs in the context of many other services that are available to the family.

The program is state wide and administered through the 55 county Community Mental Health (CMH) boards. In addition to the cash subsidy the families have access to other core services. They include: case management services, respite and sitter services, parent training and education, physical, speech and occupational therapies, financial services, assessment and evaluation, therapeutic mental health, support groups, and crisis intervention.

Every family receives case management services but the availability of the other services may vary by geographical location. Either the service may be sparse/underdeveloped or overcrowded involving waiting lists. For the most part, the latter has not been a major problem.

The number of children being served demonstrates the level of commitment to family support in the state. Funding for FSSP has been relatively stable over the years, and it has received increases. However, this has not occurred without the constant vigilance of the advocacy groups.

Implementation Issues: The FSSP in Michigan is a family support program for individuals with developmental disabilities. The cash subsidy is available to families with children who must meet educationally defined categories. This categorical system is aimed at targeting services for children with complex and multiple needs. Multidisciplinary teams within the special education system provide the required certification. These categories are somewhat narrower than the federal definition of developmental disabilities but broader than the definition of mental retardation.

Michigan has a solid adult service system and integrated residential placements. This system provides for a transition when a child served by the cash subsidy reaches eighteen. Nevertheless, Michigan's family support program could be viewed as a program with some eligibility limitations.

Medicaid Policy: Michigan has a Model Waiver Program which is approved for up to 200 individuals with developmental disabilities who are between the ages of 0-26. Eligible persons are those who would require the care of an ICF-MR if there were no waiver program. Presently all enrolled individuals live with their natural/adoptive families. However a recent amendment allows children/youth who are in foster care to be eligible for Model Waiver coverage if they have a formal plan to permanently unite them with their natural or adoptive families. The FY 1989 budget is approximately $5 million.

Michigan also has a larger waiver program approved for up to 2600 individuals which targets persons (adults and children) who without the waiver program would require ICF-MR care and whose primary care needs can be addressed with habilitation training services.

For both the Model Waiver and the Habilitation Waiver persons must be eligible for Medicaid. However, the Model Waiver waives the SSI parental deeming requirements. The contact person for these programs is Bill Harrison, (517) 373-2741.

Related Efforts: The term "family supports" is somewhat unique to the field of developmental disabilities and used largely by the departments of mental health and developmental disabilities. However, activities aimed at enhancing family life for people with special needs are gaining momentum in other state agencies:

The Department of Education. This department is responsible for implementing P.L. 99-457 and the **Individual Family Service Plan**. The IFSP is an important legislative vehicle for including the input as well as the needs of the entire family in the educational planning process. The contact person is Jackie Thompson, (517) 373-8483.

The Department of Public Health, Division of Maternal and Child Health. This state agency has a **Services to Children with Special Health Care Needs** program for children with complex medical needs. The program's contact person is Joan DesChamps, (517) 335-8961.

Evaluation: Michigan has conducted several studies since their seven year involvement with family supports. Two base line studies and subsequent updates are part of the evaluation. The analysis provides an in-depth look at problem areas, service utilization, and planning strategies for future direction. The Evaluation Division of the Department of Mental Health is currently conducting an Evaluation of Quality of Family Support Services from the perspective of the parents. Parents are mailed satisfaction surveys which are also included in the reports. The central office of the Department of Mental Health monitors the administrative functions.

Parents have an active role in the planning and design of the program and their role is growing. Between 25-30 CMH boards have family support advisory committees. Parents also participate in the public health program, Services to Children with Special Health Care Needs.

Future Directions: Michigan's FSSP has embodied the concept of family empowerment and has provided a national demonstration of the merits of flexible family suppports. The Department of Mental Health recognizes that it must work on making core services more readily available and accessible. The services should move beyond preventing institutionalization and other family crises and become part of a normal service system available to families. The program is also concerned with accommodating more families and broadening the definition of those individuals being served. To assist with the state efforts the DD Council has built activities in its 1990-91 plan to help increase the array of family support options statewide.

Lessons Learned: Michigan has seven years of experience and an evolving system of family supports. Michigan's program started from parent groups and organizations. This was key in launching the program. Also, once a state has a family support program, it must constantly reevaluate the goals and outcomes, keep the supporters of the program interested in its progress, and prevent financial cutbacks.

More than financial assistance the Michigan Program provides a symbolic value to families and gives them respect and control of their lives. The program indicates an understanding by the state of the needs of families and an appreciation of their roles as caretakers.

Materials Reviewed

Family Support Services in Michigan: An Evolving System, Michigan Department of Mental Health, July, 1987 (a report from a study conducted by the Michigan Department of Mental Health analyzing the availability/ accessibility of services).

Family Support Services: Report on Meta Evaluation Study, Michigan Department of Mental Health, July, 1983 (a study of service utilization).

Family Support Action Plan, by the Michigan Developmental Disabilities Council, April, 1988.

Michigan Department of Mental Health: Report on Family Support Subsidy Program FY 84-85, February, 1986 (evaluation report, implementation issues, and recommendations).

Family Support Subsidy Act (a copy of the legislation) Act No. 249, 1983; Act No. 358, 1984; Act No. 186, 1984.

MINNESOTA

Name of Program: Family Subsidy Program (FSP)

Nature of Program: The program was authorized by Minnesota Statute: 252.37, Subd. 4., 1979.

Date of Implementation: FY 1980

Administering Agency/Contact Person: Department of Human Services, Division for Persons with Developmental Disabilities, Thomas Fields, (612) 296-2147.

Type of Program: The FSP is a cash subsidy program.

Number of Families Served: Four hundred families have received services this past year.

Eligibility Criteria: "The program is limited to families whose dependents are under the age of 22, and who are mentally retarded or have a related condition and otherwise would require or be eligible for placement in a licensed residential facility."

Services Covered/Allowable Expenses: The program provides grants to parent(s) in an amount equal to the direct costs of the services outlined in a service agreement. Grants are to assist the family to maintain the child in the family home, funding such needs as: diagnostic assessments, homemaker services, specialized equipment, therapies, transportation, pre-school programs, respite or child care, and other services and goods for which no other funding source is available.

Limit on Benefits to Individual Family: The cash subsidy is not to exceed $250 per month; except in cases of extraordinary circumstances where exceptional resources are required for a period not exceeding 90 days in a fiscal year.

Current Funding Level: FY 1989 $1,062,700 increased to $1,128,700 for FY 1990.

Background: Minnesota has a long history of providing family support. In 1976 a pilot project began which served 25 families. By 1978 family support was a permanent program.

The goals of the program are: 1) To reduce utilization and dependence on long-term care; 2) to support people in their homes; and 3) to return institutionalized individuals to their family homes.

Program Structure: Minnesota has 87 counties each with a County Human Service Agency. Each agency has case manager(s) assigned to developmental disability services. Case management is in place in every County Human Service Agency. The cash subsidy is available in all 87 counties. Currently families living in 46 counties participate.

Priority to receive the FSP is given to people with severe disability, people who are at greatest risk of out-of-home placement, and to families with the capability of providing care. It was noted that there are problems in making these decisions. It is difficult to compare families and often stress is relative.

The FSP is publicized through the ARC's, by social workers in the hospitals that provide developmental disability services, and by word-of-mouth. The community services offered by the County Human Service Agencies and the FSP are very flexible and family driven.

Implementation Issues: As is true in many of the other states, Minnesota's resources vary from region to region. Respite care is more difficult to access in rural areas and case loads are very high across the state, making case management services less effective. Between 15,000-17,000 persons received case management services through the County Human Service Agencies.

A pilot project was started to train parents to become their own case managers. This might help alleviate the pressure of the professional staff while allowing parents the opportunity to have more control.

The FSP has increased the number of eligible families by 120 in the past two years; 25 new families were added to the program this year. Minnesota has one of the country's oldest family support system. It also has a system that is growing and changing to meet the needs of its families.

Medicaid Policy: Minnesota has several Medicaid waivers that demonstrate the state's commitment to community/family care:
1) The Community Based Waiver has served 2000 persons with mental retardation of all ages;
2) The Elderly Waiver to prevent nursing home placements;
3) (CADI) The Community Alternatives for Disabled Individuals;
4) (CAC) Community Alternative Care Waiver; and
5) The Tefra Waiver for children with medically complex needs.

The waivers for persons with mental retardation include the following services: case management (mandatory), day training/vocational, respite care, homemaker services, and rehabilitation services. Contact Bob Prouty for the

Community Based Waiver, (612) 296-2136; Phyllis Zwieg for CAC and TEFRA, (612) 296-2916; and Linda Adams for CADI, (612) 296- 1551.

Related Efforts

The Departments of Children and Youth Services and Health. These departments provide temporary child care for handicapped children. The crisis nursery was a federally sponsored initiative.

The Department of Education. This department is responsible for implementing PL 99-457. There are state and local coordinating committees. The contact persons are Jan Rubinstein or Sandra Fink, (612) 296-7032.

The Department of Health. This agency has a **Crippled Children Program**, which provides diagnosis and treatment for children with medically eligible conditions. The contact person is Carolyn McKay M.D., (612) 623-5166.

PACER (Parents Advocacy Coalition for Education Rights). This training program was the first of its kind in the nation and has inspired many models in other states. Contact: Marge Goldberg, (612) 827-2966.

The Developmental Disabilities Council. This organization has conducted a special training series, **Partners in Policy Making**, aimed at involving consumers at the early stage of program design.

The Department of Human Services. A staff person has been assigned by this department to coordinate respite care and provide a resource center.

These activities demonstrate the state's commitment to family and improving the human service delivery system.

Evaluation: The strengths of the Minnesota program are threefold: First, the families have complete control over the cash subsidy which instills the parents with respect and dignity. Second, families with the greatest need are being served. And third, the FSP fits in well with the Waiver programs and other state programs because eligibility for the FSP does preclude eligibility for the other programs.

In spite of the benefits of the Minnesota program it has its limitations. First, it does not reach every family who is need of the service. Second, the FSP stops when the child becomes 22 years old. Finally, the FSP has a lengthy application process, and there is a waiting list for services.

The program could be improved if it were made into an entitlement program with "no strings attached" or if the dollars were used more effectively to meet the immediate needs of the families.

The state of Minnesota has a coalition on caregiver support with representation from 75 organizations. Representatives include the elderly, persons with disabilities, and persons with mental illness. This effort keeps the state mindful of family needs for quality life.

Finally, there is an effort to examine utilization of generic services in rural areas where incidence of diagnosis-related services are low. Minnesota has a solid track record in providing services for individuals with developmental disabilities and empowering families.

Future Directions: Minnesota hopes to close all state institutions for persons with mental retardation by 1999. To accomplish this the state is dependent upon shifting Medicaid dollars to community/family supports. In concert with this effort the state has moved toward integration of persons with developmental disabilities into community life.

Lessons Learned: States must have a clear definition of what is meant by family support. There must be a genuine partnership with families. Lastly, "states must practice what they preach and put to work the rhetoric that they embody".

Materials Reviewed

Policy Analysis Series: Issues Related to Welsch v. Levine/No. 18, May, 1983 (a manuscript from the Developmental Disabilities Program, titled: The Minnesota Family Subsidy Program: Its Effect on Families with A Developmentally Disabled Child).

Policy Analysis Series: Issues Related to Welsch v. Levine/No. 20, October, 1983 (a manuscript from the Developmental Disabilities Program, titled: Respite Care: A Supportive and Preventive Service for Families).

Policy Analysis Series: Issues Related to Welsch v. Levine/No. 21, October, 1983 ((a manuscript from the Developmental Disabilities Program, titled: Summary and Analysis of Minnesota Developmental Disabilities Respite Care Demonstration Projects).

Policy Analysis Series: Issues Related to Welsch v. Levine/No. 24, February, 1988 (a manuscript from the Developmental Disabilities Program, Minnesota Case Management Study/Executive Summary).

The Development of Family Support Programs by Collen Wieck, Minnesota Governor's Planning Council on Developmental Disabilities, no date (a paper describing the philosophy and implementation of a family support program).

Partners in Policymaking for Year Three: October: 1988 - September, 1989, submitted to Minnesota Governor's Planning Council on Developmental Disabilities, May, 1988 (an application for continuation of a training project in advocacy for individuals, families, and other consumers of services).

It's Never Too Early; It's Never Too Late: A Booklet about Personal Futures Planning, for persons with developmental disabilities, their families and friends, case managers, service providers, and advocates, 1988.

A New Way of Thinking, Governor's Planning Council on Developmental Disabilities, January, 1987 (booklet describing state activities, with a historical

perspective, and policy statements about state of the art services for persons with developmental disabilities).

Toward a Developmental Disabilities Policy Agenda: Assuring Futures of Quality, presented by the Governor's Planning Council on Developmental Disabilities, March, 1984 (outlines future services needs for individuals with developmental disabilities).

State of Minnesota: Developmental Disabilities; 10/1/86 - 9/30/89, Three Year Plan, October 1, 1986 (describes state's activities and three year objectives).

Developmental Disabilities and Public Policy: A Review for Policy Makers, presented by the Governor's Planning Council on Developmental Disabilities, January, 1983 (booklet addressing need for community services).

Public Information brochures and a list of publications by the Governor's Planning Council on Developmental Disabilities.

MISSISSIPPI

The program described does not fall under the auspices of family support as such but at present is the only attempt in the state to begin looking at family support issues. The Developmental Disabilities Council is presently making attempts to become more involved in family support issues.

Name of Program: Infant and Toddler Program

Nature of Program: This pilot program in Mississippi is under the auspices of P.L. 94-457.

Date of Implementation: 1988-89

Administering Agency/Contact Person: Mississippi State Department of Health. Contact: Norciva Geddie, Health Department, 601-960-7427.

Type of Program: Educationally-based support services.

Number of Families Served: 80-90 children presently receive services in the pilots of this program.

Eligibility Criteria: Children 0-3 with a label of developmental disability or deemed to be at risk of being labelled developmentally disabled because of health. Must be a resident of the State of Mississippi.

Services Covered/Allowable Expenditures: Services being developed include:

- family training and support which includes parent skill development, basic discipline and problem-solving skills;
- parent/child interaction activities;
- peer parenting program;
- child development instruction on developmental levels and activities;
- special instruction--prescriptive intervention to remediate specific disabilities and special therapies on a need basis;
- psychological counseling and medical services for diagnostic purposes available upon referral; and
- case management.

Current Funding Level: $280,000.

Background: In 1987, the Department of Health was appointed the lead agency for the federal initiative. Two model sites were chosen in order to evaluate how best to develop a statewide system of service, and statewide planning efforts began.

The infant and toddler program in Mississippi developed through the passage of P.L. 94-457. In Mississippi, groundwork for its implementation was laid through activities funded by the Mississippi State Plan Grant. In the first year of the grant, the state interagency council was organized to provide necessary collaboration to lay a foundation for a coordinated system of services (there were 22 agencies involved plus parents). The council developed a mission statement and organized work groups focusing on a variety of topics. The council then sponsored a statewide conference which provided information on available services. A local interagency council was also organized in one county to establish a model for local interagency planning.

During the first year, a comprehensive needs assessment was conducted throughout the state and local agency collaboration was established to provide data to plan a comprehensive delivery system. During the second year of the grant, the state and local interagency councils continued their planning, focusing on children 0-5. The greatest need identified by the group was for intervention services for children 0-2 years of age.

Program Structure: The primary mission of this program is to provide early intervention services that are family centered, community-based and coordinated, in order to increase the quality of life for children at risk of being labelled developmentally disabled in the State of Mississippi. It also hopes to strengthen families' abilities to cope and recognize that the family is the constant in a child's life. Services should be driven by the principles that: Each family has the right to determine the nature of the services their child receives and to be actively involved in the service delivery process; and service coordination must be designed through interagency agreement so that all services contribute resources. A primary long-term outcome of the program would be that the family is able to access both formal and informal resources and service systems and that they be their own case manager and advocate.

The case manager is the person most consistent in assisting families to access needed services. Once eligibility is determined, the child and family receive a child assessment, a family assessment and finally, an individualized family service plan as determined by an interdisciplinary team. The intensity and amount of services received varies according to the families' needs. Through this plan, the duration of services and the providers as well as objectives for integrated team activities will be determined. This process is coordinated by the case manager. Team members will meet on a regular basis as determined by the service plan.

In addition, each district will have an Infant and Toddler Coordinator, who will assist case managers in the implementation of the program. It is clearly stated that families the have final decision-making power within the program.

All service providers are screened through a Credential Review Committee of the Children's Medical Program. Service providers document in a family/child log the activities, goals and noted progress on an on-going basis. Parents also review, on an on-going basis, the services they receive at six-month intervals.

Implementation Issues: Case managers receive referrals from a variety of sources such as schools, health departments, hospitals, doctors, etc., at which time the case manager reviews available materials, meets with the family and completes other preliminary intake information. Eligibility for the program is based on evaluation instruments selected with a focus on the families' needs and strengths and are done in multiple settings by a multi-disciplinary team. A child goes through several levels of screening and evaluation. Though this is an effort by a number of people from different agencies, the state Department of Health holds the ultimate responsibility for the implementation of the service plan.

There is no guarantee that all of the family's needs will be met by the services that are available, but all needs identified are included in the service plan.

Medicaid Policy: Medicaid will pay for some in-home therapy if the child is listed as home bound, which in Mississippi means that they are in need of medical support. If eligible for these services, they can receive up to 52 therapy sessions a year. The State of Mississippi wants to work on a Medicaid waiver to support medically-dependent children.

Related Efforts

Maternal and Child Health. There may be some respite grants. Contact: Sam Valentine, 601-960-7615.

Evaluation: Though there have been great strides by a few individuals to get family support services off the ground, there seems to be little over-all support.

Work groups reviewing family support services in the state indicated that family support services were very fragmented and varied and that most of the funds in the state have been directed at medical and institutional services rather than to parents. Support services, when available, usually come at a time of crisis and are determined by rigid objectives versus family-centered priorities.

Efforts for children 0-3 have been well planned. The limitations related to the unserved population remain a major drawback, yet the success of this program may prove to be the impetus for a more extensive approach to family supports.

Future Direction: The State of Mississippi through efforts of the Association for Retarded Citizens has formed a coalition that will be looking at how Mississippi might use the Medicaid waiver to support future family support endeavors; this will also be pursued in the 1990 legislative sessions.

The state needs 1) legislation to encourage agencies to plan collaboratives 2) to develop realistic goals to use public and private funding options for new services and the enhancement of existing ones and 3) To increase interagency efforts and expand local efforts that focus on parent and professional partnerships.

Lessons Learned: There needs to be a stronger focus on the value of the family as a strong and supportive unit. A lead agency should be determined to take responsibility early on in the process.

Materials Reviewed

Infant and Toddler Program Eligibility Criteria

Individualized Family Service Plan form

Mississippi Policy Development Early Developmental Services Summary of Activities, 1988 to June 1989.

Mississippi State Department of Health, Infant and Toddler Program, 11-1-88.

Mississippi State Department of Health, Infant and Toddler Program, Description of Pilot/Model Site Activities.

Mississippi State Department of Health, Infant and Toddler Program, Draft Procedures for Case Managers, Revised, June 6, 1989.

Mississippi State Department of Health, Infant and Toddler Program Overview, 11-17-88.

Mississippi State Department of Health, Infant and Toddler Program Summary.

A Proposed Model of Services for Infants and Toddlers with Disabilities or at Risk of a Disability, 6-7-89 (DRAFT).

Recommendations for Individual Service Plans Development, Implementation, and Evaluation, Mississippi State Department of Health IFSP Work Group.

Summary of the Activities and Recommendations of Work Groups of the Infants and Toddlers Program, prepared by Janet G. Larsen, November 1988 (DRAFT).

MISSOURI

Name of Program: Family support services are not a discrete category bu fal under the general Purchase of Services System (POS).

Nature of Program: Missouri does not have family support legislation. A statute exists for respite care, limiting the care to 21 days per year with special approval allowance for an additional 21 days.

Date of Implementation: FY 1976

Administering Agency/Contact Person: Department of Mental Health, Division of Mental Retardation and Developmental Disabilities (DMRDD), John Long, (314) 751-3073 ext. 484.

Type of Program: DMRDD contracts with vendor providers to provide specified services.

Number of Families Served: There is no data available that provides an unduplicated number of clients of families served. The total number for FY 1989 was 3,034.

Eligibility Criteria: An individual with a developmental disability according to the categorical definition is eligible for services, provided the onset occurred before age 18. A standard means test is used to determine financial eligibility. Payment is based on a sliding fee scale.

Services Covered/Allowable Expenditures: Under the POS system, family support services are defined with the following categories: Early Intervention Child, Early Intervention Infant, Care Giver Consultation for Early Intervention, Respite Care, Emergency Respite Care, Home Health Care, Interpersonal Counseling. POS funds are limited and some providers are not available in some parts of the state causing the services to be fragmented.

Limit on Benefit to Individual Family: Not specified. Services are based on need and availability.

Current Funding Level: FY 1989, $3,638,053.

Background: The DMRDD in Missouri currently contracts for specified services defined as family supports. It is a predefined and prescribed package of services whose purpose is to maintain the individual with developmental disabilities in their natural home. The POS system is not very flexible.

Program Structure: Missouri is divided into 11 regional service centers. The regional centers are responsible for assessment, intake, evaluation of services, and development the Individual Habilitation Plan (IHP). Among the list of services offered under family supports, the families with assistance from the case manager, can identify their own needs. Services will be based on availability of providers and/or funds. Some of the services have built-in flexibility such as respite care, which can be provided in-home or out-of-home. Each region has a regional council comprised of consumers and a regional coordinator. They are funded through subgrants from the Missouri Planning Council for Developmental Disabilities.

Implementation Issues: The MPCDD is continuing to advocate for a family support system that includes a voucher subsidy system for families. Currently, services are fragmented and vary from region to region. The funding is administered regionally which allows for discrepancies. The Council has drafted and recommended a family support policy to the DMRDD. The Council has also recommended a change in the developmental disability definition from categorical to functional.

Medicaid Policy: Missouri has a community based waiver that serves individuals with developmental disabilities. In FY 1989, 1,397 persons were on the waiver, however, only 57 of them lived with their natural families. The contact people for the Medicaid waiver are Leslie Jordan, Dept. of Mental Health, (314) 751-4730, or Katie McLain, Division of Mental Retardation and Developmental Disabilities, (314) 751-4054.

Related Efforts

Departments of Mental Health, Health, and Education. In Missouri early intervention services for children 0-2 (PL 99-457) are coordinated by these departments. This collaborative effort promotes a comprehensive approach and continuity of care. The coordinating position is staffed at the DMRDD; contact person: Donna Evert, (314) 751-4054.

The Department of Elementary and Secondary Education. This agency has a program entitled **Parents as Teachers** for parents of preschool children. The contact person is Debbie Murphy, (314) 751-2095.

The Department of Health. This department has a child and family program for early intervention called **Project First Step**. The contact person is Mary Johnson, (314) 751-6246.

Evaluation: Family support services in Missouri are limited because of limited funding. The role of parents at the state level is limited. Their involvement is more evident at the local level where they participate in support groups and in IHP meetings. The regional councils are comprised of parents and consumers who have input into the service delivery system. The state monitors its providers through Quality Assurance/Licensure standards.

Future Directions: The DD Council of Missouri is aware of the state's limited family support program. Efforts have been directed toward organizing consumers and advocates to develop a more comprehensive system. For FY 1991, $500,000 of new money is being requested to the DMRDD for family support to include a voucher system.

Lessons Learned: Developing a family support system requires starting at the grass roots level and organizing parents.

Materials Reviewed

Division of Mental Retardation and Developmental Disabilities, Purchase-of-Services Catalog, FY 1990, effective date: July 1, 1989 (description of designated family support services).

Position Paper on Family Support Services: A Policy Framework, prepared by the DD Council, 1/12/89.

Families Speak Out: State wide Results, October, 1988. State wide Forum and Survey Results Concerning the Special Needs of Persons with Developmental Disabilities and their Families, prepared by the DD Council.

Missouri Department of Mental Health, Division of Mental Retardation and Developmental Disabilities, Five-Year Strategic Plan: Fiscal Years 1989 through 1993, October 1988 (manual describing state's future objectives re: service delivery to persons with developmental disabilities).

Family Support Expenditure Analysis FY 88, services delivered by region.

MONTANA

Name of Program: 1) Family Training and Support Services
2) Respite Care
3) Specialized Family Care.

Nature of Program: Statewide ongoing services

Date of Implementation: Montana has had family-centered developmental services since 1975.

Administering Agency/Contact Person: Richard Van Haecke, Early Intervention Specialist, Department of Montana Department of Social and Rehabilitation Services, PO Box 4210, Helena, MT 59604, (406) 444-2995.

Type of Program: 1) Family Training and Support: A home-based service and training program 2) Respite Care: A reimbursement program and 3) Specialized Family Care: Services

Number of Families Served: In FY 1988/89: 1) Family Training and Support: 476 families; 2) Respite Care: 542 Families; and 3) Specialized Family Care: 73 families (82 families estimated in current year).

Eligibility Criteria: 1) Family Training and Support is available to families caring for a child (birth through 18 years of age) with a developmental disability or a child (birth to five years of age) who is at risk of developmental delays; 2) Respite Care is available to families who have a child or adult family member with developmental disabilities; and 3) Specialized Family Care serves natural or foster families who have a child (less than 22 years of age) with multiple and/or severe developmental disabilities presently placed out of the home or in jeopardy of placement .

Services Covered/Allowable Expenditures: 1) Family Training and Support: Services and resources available to families through this program include child- and family-focused training, adaptive equipment, evaluations, therapies, case management, social-emotional support, information and referral; 2) Respite Care: Temporary in- or out-of-home care; and 3) Specialized Family Care: primary service is case management; additional services can include, but are not limited to, medical treatment, respite and day care, minor home modifications, therapies, home maker services, personal care attendants, and advocacy.

Limit on Benefits to Individual Families: 1) Family Training and Support: There is no fee for this service; 2) Respite Care: Families may be reimbursed up to a maximum of $350 per year for respite; 3) Specialized Family Care.

Current Funding Level: For FY 1989/90: 1) Family Training and Support: $1,351,659; 2) Respite Care: $284,632; and 3) Specialized Family Care: $910,912.

Background: Montana has provided a variety of services for children with developmental disabilities and their families since 1975. The service delivery system in the state has evolved to become primarily home-based, family-oriented, and designed to meet Montana's unique circumstances: Small dispersed population with few population centers; vast distances between centers; and a limited number of professionals. Services are designed to help families become independent in raising their children. To the extent possible, the goal of services is to teach families how to become the primary change agent for their children.

Program Structure: The Montana Department of Social and Rehabilitation Services administers programs for persons with developmental disabilities and their families through its Division of Developmental Disabilities. Three administrative regions contract with a network of private, not-for-profit provider agencies. Families have an official say in policy making and service delivery through their participation on the Regional Councils. Services are monitored by the Division of Developmental Disabilities at the field and central office levels. All service providers are required to be surveyed by the Accreditation Council of Developmental Disabilities. Approximately 700 families receive some form of developmental service. While the ages of children in these families range from birth to 22 years of age, the vast majority are children under the age of six.

1) Family Support and Training: This service is the cornerstone of the Montana service delivery system. The goals of the Family Training Program are: 1) To provide home-based training for the child and family; 2) to provide information about and connection to services and resources; and 3) to keep the child at home and the family together. A family trainer with generalist skills is the main contact with families. This individual conducts child and family assessments, acts as a case manager, and provides training to the family on how they can best work with and teach their child. Following an initial assessment, an Individual Family Service Plan is developed. This plan outlines the training and services needed by the family. When more in-depth evaluations or services are needed the family is referred to the appropriate specialist(s).

2) Respite Care: The goals of this program are: 1) To provide a temporary break from the pressures of parenting; 2) to provide care in an emergency situation; and 3) to connect parents with qualified respite providers. Families pay for respite care and are reimbursed on a monthly basis (maximum annual respite allotment per family is $350). Families must use registered respite providers; families may use their own private care givers if they first register them with the provider agency. It is permissible for providers to be relatives.

3) Specialized Family Care: The purpose of this program is: 1) To maintain children with intensive needs in natural or foster homes; 2) to promote the deinstitutionalization of children with intense care needs; and 3) to make use of community resources in providing services to these children and their natural or foster families. (When a child can no longer be cared for by their natural families, this program assists in their placement with a specialized foster family rather than in a group home, institution, or nursing facility.) Specialized Family Care refers to an array of services which are provided in the

family's home setting or community. Services needed by the family are stated in a specialized family service plan. Case management is a vital component of this program; families receive assistance in locating, coordinating, and monitoring the services they need in order to care for their special needs family member at home. This program is funded through a Title XIX Medicaid Waiver. The average cost of this program per family is approximately $10,000 per year.

Implementation Issues: Services to persons with developmental disabilities and their families have not been an entitlement in Montana. (With the implementation of PL 99-457 this situation will be changing for children under the age of three.) The Division of Developmental Disabilities is limited in the services it can fund by the appropriations passed by the state legislature. Generally, when eligible individuals apply for services they must wait until openings in existing programs occur or additional resources are appropriated. The length of time spent on waiting lists varies from service to service, but in most cases services are provided within months of application. About 75 children birth to three were on waiting lists for services last year. The legislature appropriated an additional $250,000 for early intervention services to this group. Approximately 200-300 children and families are on waiting lists for other developmental services.

In addition to lack of funds, services in Montana are also constrained by the state's vast geography and small widely dispersed population. Specialized professional resources are extremely limited. For example, the 17 county area of eastern Montana has only one pediatrician.

With the implementation of PL 99-457 there has been increased attention in Montana to coordination of services to young children with disabilities. The state's Part H Grant has been administered through the Division of Developmental Disabilities. The state's Interagency Coordinating Council includes parent representation.

Medicaid Policy: In December 1981, Montana became the first state with an approved waiver program. In the years since the waiver there has been a moratorium on licensing and certification in Montana's ICF/MR program. The net effect of the waiver program has been to give the state an alternative to institutional care. The Community Home-Based Medicaid Waiver: the Waiver is used to fund Specialized Family Care, as well as other services. Montana does not currently have a Katie Beckett Option. For information on Medicaid issues contact: Susan Jackson, Title XIX Coordinator, (406) 444-2995.

Related Efforts

Parents, Let's Unite for Kids (PLUK). This is a non-profit statewide organization for Montana families who have children with disabilities or chronic health problems. PLUK activities include organizing parents to influence the state legislature to support development of services for children with emotional and behavioral disabilities. Support to parents who have children with emotional disabilities is provided through informal parent groups conducted at least twice monthly and through technical assistance for newly forming and ongoing support groups. The organization has an 800 number for information, issues a newsletter, and is developing fact sheets on resources and issues related to children with emotional disabilities and their families. A pilot project is underway to train parents to become effective advocates for their children. For more information, contact: Kathryn Keller, Parents, Let's Unite for Kids, EMC/MCHC, 1500 N. 30th, Billings, MT 59101-0298, (406) 657-2055.

Evaluation: Montana appears, through its Family Training and Support and Specialized Family Care, to have found a model of service that is suited to the state's size (only Alaska, Texas, and California are larger) and small population (809,000). With the information available, it is not possible to judge whether the quality and frequency of these home-based services are adequate to meet family needs. If prevention of institutional placement is a measure, Montana's services to families would appear to be successful. Currently, no children under the age of two and only seven children ages 3-18 reside in the state's Intermediate Care Facilities for the Mentally Retarded. However, approximately 50 children (average age 14) live in group homes.

Overall, there are not enough resources, either human or financial, to support adequate services for Montana families who have a family member with a disability. Respite care would seem to be inadequately funded: How much in the way of real relief can a maximum family allocation of $350 a year buy? Families whose children have complex and multiple needs are hard pressed to find the specialized assistance they may need; this is especially true for families who live in more rural and isolated areas of the state. The majority of the 700 Montana families receiving services funded by the Division of Developmental Disabilities have children under the age of six. Minimal resources are allocated for families caring for older children and adult family members with developmental disabilities. Little if anything seems to be available to help families caring for a family member who has a disability other than a developmental disability.

Future Directions: PLUK (see Related Efforts Section) will be working to increase state services for children with emotional and behavioral disabilities. To meet the legal requirements resulting from PL 99-457, Montana will need to allocate additional resources for services for children from birth to three years of age who have developmental disabilities or who are at risk of developmental delays.

Lessons Learned: Montana's model for family oriented, home-based services using the skills of a well trained generalist make sense for a large, sparsely populated state with vast distances between population centers. Montana's experience in working with families may be one worth sharing with other state's with similar demographics (i.e. Wyoming, Nevada, South Dakota).

Material Reviewed

Contract between Montana State Department of Social and Rehabilitation Services and the following programs: Family Training and Support Services, Specialized Family Care, and Respite Care, Effective July 1, 1987- June 30, 1989.

Early Intervention Services in Montana, an Annual Report to the Governor of Montana and the Secretary of the U.S. Department of Education, submitted by the Interagency Coordinating Council, the Montana Department of Social and Rehabilitation Services, Helena, MT, 1988.

Focal Point, the Bulletin of the Research and Training Center to Improve Services for Seriously Emotionally Handicapped Children and Their Families, Vol. 3, #2, Winter/Spring 1989.

June 14, 1988 Letter from Mike Hanshaw, Chief, Management Operation's Bureau, Montana Developmental Disabilities Division to Donald Kates, Resource Specialist, Georgetown University re: information on early intervention services.

Montana's Proposal to Receive FY 89 funds under PL 99-457; 6) Program brochures: Developmental Educational Assistance Program, Region II Child and Family Services, Special Training for Exceptional People, Western Montana Comprehensive Developmental Center.

NEBRASKA

Name of Program: Disabled Persons and Family Support Program

Nature of Program: Reimbursement for disability related family expenses; the program may either reimburse the disabled person or caregiver or provide direct payment to the provider of the service.

Date of Implementation: Legislature passed a bill establishing the program in 1981, however, funding for the program did not occur until the FAll of 1983.

Administering Agency/Contact Person: Nebraska Department of Social Services, Box 95026, Lincoln, Nebraska 68509-5026, in Lincoln (402) 471-3121; Toll Free Number: (800) 358-8802, Lenore Spencer

Type of Program: Ongoing state operated program

Number of Families Served: In FY 1989, 333 families

Eligibility Criteria: The program serves three populations: 1) Families who provide care for a disabled family member (either adult or child) living with them who need some form of support to keep the family together and prevent out-of-home placement; 2) Persons who are disabled and employed (or could be employed), earning at least $300 per month, who need some form of support to maintain employment; or 3) Limited number of persons living alone or with a non-relative caregiver who need assistance to maintain their independent living situation. Those applying must show they have explored all other possible sources for assistance. To meet financial eligibility criteria, families must have an income below Nebraska's median family income (for a family of four this would mean a gross monthly income of less than $2,623). Medical information must be supplied demonstrating a severe and chronic disability.

Services Covered/Allowable Expenditures: The program may authorize payment for disability related expenses such as: architectural home modifications, attendant care, non-medical costs incurred during treatment, counseling or training, home health care, housekeeping, special equipment, respite care, and transportation. Other types of support may also be considered based upon individual need and circumstances. Medical bills are not covered by this program.

Limit on Benefits to Individual Families: $300 per month/per family averaged over the number of months in the eligibility period.

Current Funding Level: for FY 1989-90: $300,000

Background: In Nebraska support to families is provided primarily through the Department of Social Services. The Department of Public Institutions and Office of Mental Retardation provide services primarily for adults. Nebraska's Office of Mental Retardation has six regional boards, two of these have recently offered respite care services for families caring for a child with mental retardation.

Program Structure: The stated purpose of the Disabled Persons and Family Support Program is to provide services which are cost effective, preserve the family unit, and promote independent living. Individuals learn about the program by word of mouth from other families, advocacy groups, and local social services and schools. There is no active outreach to recruit families to this program.

Families applying to the Family Support Program may do so through their local Social Services office or at the state office in Lincoln. Applications for family support are reviewed monthly at the state level by a team comprised of representatives from the Departments of Vocational Rehabilitation, Education, Health, the Developmental Disabilities Council, Independent Living Center, Office on Aging, Easter Seals Society, and Department of Social Services. In reviewing applications, the team addresses the issue of service coordination and attempts to ensure that families are receiving whatever additional supports and services that may be available to them. Families found ineligible for family support shall have the opportunity for a fair hearing before the Department of Social Services.

General fund dollars provide 100% of the funding for this program. Originally funding for the program was proposed to eventually be $500,000. The first year $180,00 was allocated. In the last fiscal that was increased to $300,000.

Implementation Issues: Initially, getting the word out about the program was a major problem; and then when families finally began applying, the program ran out of funds. Currently the program has no waiting list, but projections for the next year indicate that the program may not be able to meet the demand for services. There have been a few problems with paperwork and timely reimbursement.

Medicaid Policy: The State has three Medicaid waivers, including one for children with disabilities other than developmental delays and one modek waiver for children with mental retardation. In addition, the State plan allows children with high medical needs to be Medicaid eligible without considering parental income (the TEFRA option). For Medicaid Information contact: Mary Jo Iwan, the Department of Social Services, Box 95206, Lincoln, Nebraska 68509-5026, (402) 471-9345.

Related Efforts

Special Education Services. For the past ten years, these services have been mandatory in Nebraska from the date of diagnosis. A special education home teacher provides services and supports to families of young children. Through PL 99-457, Nebraska has an interagency coordinating council examining issues affecting children 0-3 and their families. Contact person for their activities is Jan Thelen, The Department of Education, (402) 471-2471.

Office of Mental Retardation. As previously mentioned, this agency provides respite care services through two (those serving Lincoln and Omaha) of its six regional boards. Additional information may be obtained from David Evans, Office of Mental Retardation, (402) 471-2851.

Families participate in policy decisions through representation on the Interagency Coordinating Council for PL 99-457, the Developmental Disabilities Council, and Advisory Boards to the Office of Mental Retardation and Medically Handicapped Children's Commission.

Evaluation: The greatest strength of Nebraska's Family Support Program is its flexibility in assisting families. Families, not caseworkers, determine their needs and set their own priorities for assistance. Paperwork and bureaucratic interference are kept at a minimum for families. Statewide administration which utilizes a team approach in reviewing family support applications, helps to ensure that families receive those services to which they are entitled and that the services are coordinated. Family response to the program has been extremely positive. The state believes the availability of family support has enabled families to stay together and has prevented out-of-home placements.

Because Family Support is administered centrally and is strictly a reimbursement program with no case management component, there is no ability to connect families with local services or hook people into their communities. Other program weaknesses cited include: 1) a somewhat lengthy lag time for reimbursement; 2) inability of families to deduct disability related expenses (i.e., medical bills, special equipment purchases) in order to meet financial eligibility requirements; 3) little or no outreach to inform families about the program; and 4) lack of parent involvement in program planning or monitoring.

Future Directions: Through the Part H activity there has been a movement in Nebraska to determine service responsibility and to coordinate the efforts of the various state agencies. The Department of Education is beginning to ask other state agencies for assistance in helping families who have children with disabilities. The state's Office of Mental Retardation has been reluctant to extend their services to children or families, seeing this as the Department of Education's responsibility. How this issue gets sorted out remains to be seen.

Lessons Learned: Based on Nebraska's experience, the following points should be kept in mind when establishing family support: 1) keep the application process very simple; 2) make the service "family friendly" (e.g. use an 800 number where families can call for assistance); and 3) most importantly, keep the program family controlled; allow families to decide what it is they need.

Material Reviewed

Brochure for the Disabled Persons and Family Support Program, general information sheets about the program from the Department of Social Services, authorizing family support legislation, and Legislative Bill 637 establishing a Family Policy Act for Nebraska.

NEVADA

Name of Program:
1) Family Preservation Program
2) Respite Care
3) Case Management

Nature of Program: Ongoing statewide programs

Date of Implementation: 1) Family Preservation Program: 1981; 2) Overnight respite care has been available since the 1970's; funding for statewide respite, which includes day care, began July 1, 1989.

Administering Agency/Contact Person: Jack Middleton, Division of Mental Hygiene and Mental Retardation, Kinkead Building, Room 403, 505 East King Street, Carson City, NV 89710, (702) 885-5943.

Types of Programs: 1) cash assistance, 2) temporary care in- or out-of-home, and 3) assistance in connecting individuals and families with needed services.

Number of Families Served: 1) Family Preservation Program: 70; 2) Respite Care: Approximately 200 families were served in FY 1988; and 3) Case Management: 54 families in rural Nevada received case management services. Statewide statistics for this service are unavailable.

Eligibility Criteria: 1) For the Family Preservation Program, the parents or relatives must be caring for a profoundly mentally retarded person in their home and the family must be having difficulty paying for the care or support of this individual. 2) Respite Care is available to families caring for a family member with mental retardation in their own homes. Financial assistance for respite care is on a sliding scale (e.g. A family of four with an annual income less than $30,000 would be eligible for a 100% coverage of respite care, a family of the same size with an income over $60,000 would receive no assistance.) 3) Case Management -- individual must be diagnosed as mentally retarded.

Services Covered/Allowable Expenditures: For the Family Preservation Program, families have complete discretion as to the use of the money; in applying for the program they must, however, state how they intend to use the money.

Limit on Benefits to Individual Families: 1) Families participating in the Family Preservation Program may receive up to $260 a month. 2) There is a sliding fee scale for respite care.

Current Funding Level: 1) Family Preservation Program: $178,478 in FY 1989/90, 2) Respite Care: $66,000 in FY 1989/90, and 3) Case Management: this service is not a separate line item in the Division of Mental Hygiene and Mental Retardation budget.

Background: Nevada was one of the first states in the country to provide a financial subsidy for families caring for a person with mental retardation.

Program Structure: The service system in Nevada differs from most states in that one agency, the Division of Mental Hygiene and Mental Retardation, administers services for persons with mental retardation and another agency, the Division of Rehabilitation, administers services for individuals who have other developmental disabilities. Services through the Division of Mental Retardation are provided at the local level by one of three regional offices.

The purpose of the Family Preservation Program is to provide financial assistance to enable families to continue providing home care for a family member with profound mental retardation. Regulations state if, in a given fiscal year, there is not enough money to make full payment to all families who qualify for the program, the Division shall prorate the payments so that the same prorated amount is allocated for each family. In this way the state takes all comers for services and does not have a waiting list.

Participation in the Family Preservation Program has an additional advantage of opening up SSI and Medicaid to families who might not otherwise be eligible. Regulations preventing a family's income from being deemed twice, enable families (whose income in other circumstances would be too great) to apply for assistance from these Federal programs. Qualifying for SSI and Medicaid ultimately results in much greater resources and services for individuals and their families than those which might be purchased with the Family Preservation allotment.

Respite Care coverage has recently been extended to include day care. The decision to expand this program came out of last year's successful pilot experience in the Las Vegas area.

Case management services, including transitional planning for individuals moving from school to the adult world, is one component of the Division's services. Families receive information about existing state and federal programs and are assisted in applying for services. Case managers advocate on the behalf of individuals and their families to receive needed services and resources.

Implementation Issues: For the most part, families must locate their own respite care providers; the families are expected to pay the provider for their portion of care and the providers are reimbursed by the state for the remainder. Regulations stipulate respite providers must be licensed by the state. It is, however, permissible for families to use friends and relatives as providers.

The provision of services is greatly affected by the state's demographics: Nevada is the seventh largest state in the union and has a population just over a million. Nevada families living in smaller communities have a difficult time finding services, the situation is especially acute for those caring for family members with complex medical problems or specialized needs.

Medicaid Policy: Nevada has a Community and Home-Based Medicaid Waiver, a Katie Beckett Option, and a Medicaid Waiver for Physically Disabled Individuals. Information about Medicaid can be obtained from: Mary Lee, Nevada Medicaid Office, State Division of Welfare, 2527 North Carson Street, Carson City, NV 89710, (702) 885-4698.

Related Efforts

The Developmental Disabilities Council. This organization operates a program to provide individualized assistance to persons with developmental disabilities and their families. To receive assistance, individual service plans must be completed, outlining specific resources or services required. For more information about this program contact: Ms. Donny Loux, 505 East King Street, Room 502, Carson City, NV 89710, (702) 885-4440.

Evaluation: Nevada should be commended for its leadership in establishing the Family Preservation Program. The Program is both flexible and family-controlled, allowing families to identify and purchase those services and resources that can best assist them in caring for their family member at home. However, because this program is limited to families caring for an individual with profound retardation, many Nevada families who could benefit from the Family Preservation Program are not eligible to apply.

The state's extension of respite services to include support for day care should be a benefit to families. The respite care licensing regulations, requiring providers to collect partial payment from families and bill the state for the remainder, may prove cumbersome and ultimately a stumbling block in recruiting and maintaining care givers.

While the state has slowly been expanding services to families, Nevada is far from meeting the needs of its families who are caring for individuals with disabilities. The available programs (the Family Preservation Program, Respite Care, and Case Management) serve only a very small number of families needing support and services.

Future Directions: The Nevada Division of Mental Hygiene and Mental Retardation currently has no plans to expand its Family Preservation Program. As families become more aware of respite care, it is expected the increased demand for the service will result in a request to the legislature for increased allocations in this area. As the director of Mental Retardation services for rural Nevada stated about Nevada's respite care program, "We're dealing with just the tip of the iceberg."

A special legislative subcommittee has been appointed to review Nevada's organizational structure for community based services administered by the Division of Mental Hygiene and Mental Retardation. The subcommittee's report is due Fall of 1990; their findings may have an impact on services for Nevada families caring for a family member with mental retardation.

Lessons Learned: NA

Materials Reviewed

Nevada regulations for the Family Preservation Program, Draft Regulations for Family/Respite Care.

NEW HAMPSHIRE

Name of Program: 1) Family Support Services, 2) Respite Care, 3) Early Intervention Services, and 4) Case Management.

Nature of Program: New Hampshire law RSA 171-A Chapter 255 establishes a network of family support services.

Date of Implementation: Family support legislation was passed in 1989; other services have been available for more than a decade.

Administering Agency/Contact Person: Alan Robichaud, New Hampshire Division of Mental Health and Developmental Services, 105 Pleasant Street, Concord, NH 03301, (603) 271-5003.

Type of Program: There is a combination of support services provided to families who have a family member with disabilities:

Number of Families Served: Approximately 2,000 families; 1,100-1,200 used respite care; 1,052 were enrolled in early intervention programs; and 300-400 families received family support services through programs operated by four area agencies.

Eligibility Criteria: 1) For respite care and case management services eligibility is limited to individuals who are developmentally disabled ; 2) early intervention services are provided for children 0-3 years of age who are developmentally delayed or at risk of a developmental delay; and 3) family support services eligibility criteria are in the process of being established.

Services Covered/Allowable Expenditures: Family support services can include, but are not limited to information and referral, individual and family centered assistance (therapies, home modifications, specialized equipment), respite care, education and training, emergency, and outreach services.

Limit on Benefits to Individual Families: As yet no dollar limit on family services has been established.

Current Funding Level: In FY 90 New Hampshire has allocated a total of $3,712,270 for family support, early intervention, and respite services (Included in this total is money allocated in the family support legislation: $500,000 for FY 90; an additional $500,000 has been allocated for FY 91).

Background: During its 1987 Session, the New Hampshire Legislature created a task force to study family support issues. The New Hampshire Legislative Task Force on Family Support was in large measure responsible for the creation and passage of family support legislation; their findings greatly influenced the language of the law and its strong values statements about families and persons with disabilities.

New Hampshire is one of a few states that provides early intervention services to all children with disabilities, birth to three, without regard to type or level of disability.

Program Structure: Family support services in New Hampshire are funded by state dollars which are administered by twelve regional area agencies. State regulations guide the provision of services; however, there is a great deal of regional discretion on how services are delivered and what they look like. Program monitoring is conducted by the Division of Mental Health and Developmental Services' Quality Assurance unit.

Families will have input to program planning and monitoring through their participation in regional family support councils. The family support network mandated in the state's 1989 legislation calls for the creation of 12 regional family support councils, comprised of families who have a family member with disabilities. A family support coordinator will be available in each of the state's developmental service regions to assist families in connecting with specialized and generic services. To date 116 family members have been appointed to serve on these regional councils. The councils will assist the area agencies in identifying family needs and developing a regional plan for the family support services. The regional council will also serve as an advisory group to the family support coordinator to be hired in each region. A representative to each of the twelve councils will serve on a statewide family support advisory council to the New Hampshire Division of Mental Health and Developmental Services.

As stated in the 1989 family support legislation: "The general court recognizes that families are the greatest resource available to individuals who are disabled, and they must be supported in their role as primary care givers. Supporting families in their effort to care for their family members at home is more efficient, cost effective, and humane than maintaining people with disabilities in institutional settings." The legislation also includes a list of principles relative to supporting families, including a recognition that family support must: Focus on the entire family; be sensitive to the unique needs and strengths of individual families; build on existing social networks; and encourage the integration of people with disabilities into the community.

Implementation Issues: Because family support legislation is so recent, implementation is only just beginning. In setting up the state's family support network, New Hampshire will be able to draw from the experience of four successful existing family support programs. There is a strong feeling at both state and local levels that to be effective family support must be flexible and responsive to individual family needs. At this point, New Hampshire seems willing to adopt a "whatever it takes" philosophy to help families care for disabled family members at home. To ensure that this occurs, area agencies are lobbying the state to keep paperwork and other bureaucratic program

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requirements at a minimum. Eligibility criteria have yet to be established; families caring for children or adult family members with developmental disabilities will certainly be eligible for family support services; how available these services will be to families who have family members with other disabilities is still in question.

In anticipation of a projected revenue shortfall, the Governor of New Hampshire in October of 1989 called for 2.75% cut in all existing state budgets and asked for state departments to prepare budgets showing 5 and 10% cuts. New programs, including family support services, have been temporarily frozen until the revenue situation is ironed out. How soon the state will be able to honor its commitment to families is not yet known.

Medicaid Policy: New Hampshire was granted in 1983 a Title XIX Community Based Services Waiver. This waiver has been used as the funding mechanism for supporting deinstitutionalization, with the primary emphasis on community residential services for adults. In 1989 New Hampshire was granted a "Katie Beckett" waiver, this option expands Medicaid coverage to a class of children (under 18 years of age) who in the absence of parental care would require nursing services or hospitalization. With this option, parental income is not a factor in determining Medicaid eligibility. The state estimates the option will extend Medicaid coverage to an additional 400 children who have severe disabilities.

The state is currently investigating the use of other Medicaid waivers, possibly a Model 200 waiver or separate Home and Community Based Services Waiver, to assist in funding family support services, respite care, and more comprehensive medical supports for individuals with disabilities. The contact person for Medicaid issues in New Hampshire is: Dan Van Kuren, Division of Mental Health and Developmental Services, 105 Pleasant Street, Concord, NH 03301, (603) 271-5009.

Related Efforts

Division of Mental Health. There are minimal support services available to families caring for a family members who have disabilities other than developmental disabilities. This Division, which is only just beginning to examine ways families can be better assisted, has a small CASSP grant and funds limited outreach services for families in crisis. The contact person for mental health programs is Dr. Tom Fox, Medical Director, Division of Mental Health and Developmental Services, 105 Pleasant Street, Concord, NH 03301, (603)271-5049.

The Division of Children and Youth Services. This state agency operates a small, successful outreach program to families in crisis. **The Homeward Bound Program** has an annual budget of only $23,000. In the past two and half years 58 families have been assisted through this intensive family systems based treatment. The program is only available in Rockingham County, family participation must be voluntary and there is no income criteria. Severe behavior problems of a child in the family is the primary reason for referral to the program. The program also provides psycho-educational training for local day care centers and the Hampton school system. Contact person is Geraldine O'Connor, Division of Children and Youth Services, Health and Human Service Building, 6 Hazen Drive, Concord, NH 03301, (603)271-4693.

The Division of Public Health Services. Through its **Bureau of Special Medical Services**, this Division offers a variety of clinical and support services, as well as financial assistance (for those income eligible) to children with health problems and their families. For information about specific programs contact: Jane Hybsch, Bureau Chief, Bureau of Special Medical Services, New Hampshire Division of Public Health Services, 6 Hazen Drive, Concord, NH 03301, (603) 271-4508.

Division of Developmental Services. Two area agencies (Lakes Region and the Upper Valley) have received permission from this state agency to extend respite care to families who are caring for a medically disabled children who do not fall under the developmental disabilities definition.

The Clinical Genetics and Child Development Center. Based at Dartmouth Hitchcock Medical Center, this center has recently instituted the **Information and Resource Project**. The project provides families, educators, pediatricians, and others with medical and psycho-educational information concerning genetic and prenatally determined disabilities. A Parent to Parent resource list is maintained. For information contact: Betsey Gibbs, Butler Building, Dartmouth Hitchcock Medical Center, Hanover, NH 03756, (603) 646-8467.

New Hampshire Special Families United. This is a statewide organization offering family support, information and referral, and political advocacy for families who have a family member with a disability. For more information contact: Laurie Savage, Special Families United, P.O. Box 1141, Concord, NH 03301, 1-800-356-8881 (in state) or (603) 224-2022.

Evaluation: The New Hampshire developmental services system has made a strong commitment to families. At the state level, the Division of Mental Health and Developmental Services has provided leadership in promoting and bringing services to families: They have funded pilot programs, allowed area agencies to reallocate dollars to meet family needs, and were active and influential on the state's Legislative Task Force on Family Support. They have voiced a willingness to keep bureaucratic requirements for family support services minimal, allowing family support to be individualized and flexible. The newly passed family support legislation requires the formation of twelve regional family support councils; this should help ensure that the new services being developed for families are in fact responsive to family needs. New Hampshire families waged an incredibly strong grassroots lobbying effort on behalf of family support legislation. There should be no difficulty getting committed parents to serve on the councils.

To expand dollars available for family support, the state is investigating the use of Medicaid funds. While Medicaid may be a fertile fiscal source, New Hampshire needs to be wary that many of the Federal bureaucratic and accounting requirements may make it more difficult for the state to respond to families' needs in a flexible and individualized fashion.

Families who need assistance, but whose family member is not labeled "developmentally disabled" currently have few if any options for assistance in the Granite State. The eligibility requirements for the new family support services are not yet set and there is some slim hope that some services may be extended to more families.

The state's Legislative Task Force recognized the need for better interagency coordination to address the needs of families caring for family members who have multiple and complex problems. The Task Force recommended convening an interagency work group to review and recommend changes in practice and policy to make New Hampshire services more responsive to families. There is also a need for interagency coordination on a case by case basis for those families whose problems are catastrophic in nature. To date this level of collaboration and coordination has not occurred.

Future Directions: In the immediate future, New Hampshire's Regional Family Support Councils will be assessing family needs and developing regional plans to address these needs. In each region, family support coordinators will be hired and trained. Statewide family support services are on their way to becoming a reality. Long term work will include the refinement of support services with a continued emphasis on utilizing community and generic services to help meet family needs. New Hampshire's challenge will be to keep its services individualized, responsive, and flexible.

The state will also need to figure out how family support can be developed for those families who need services, but who are not eligible for those provided by the developmental services system. There is a beginning understanding in the state of the importance of family support. If the family support services being created in the developmental service system can demonstrate success in meeting family needs and reducing out-of-home placements, there will be a strong rationale to extend these services to other types of families. If this is to happen, it will require strong leadership and an organized and active group of parents. At this time, it is uncertain who would provide such leadership.

Lessons Learned: During the 1989 session, in one of the tightest budget years in more than a decade, the very conservative New Hampshire legislature passed a bill establishing family support services and another appropriating funds to address developmental services waiting lists. The passage of this legislation occurred through a well-organized and concerted grassroots lobbying effort conducted by New Hampshire families with support from the state's service providers and bureaucracy.

Many factors contributed to this successful legislative effort: 1) the Legislative Task Force on Family Support had studied the issues for more than 18 months and timed their report, which included strong recommendations for legislative action, to coincide with the opening of the legislative session. The Task Force's report lent a significant amount of credibility to the lobbying effort. 2) The Institute on Disabilities during the summer of 1988 conducted a Family Leadership Series for parents from around the state. A central focus of this series was legislative action. Parents attending the series formed the nucleus for the lobbying effort, providing strong leadership at the local level. 3) Families joined with the New Hampshire Developmental Service Providers group supporting their efforts on the waiting list bill; the providers in turn worked on the family support bill. 4) The Institute on Disabilities, with input from the service providers, developed fact sheets and impact statements for both pieces of legislation. This provided legislators with a justification for voting on appropriation bills in lean times. 5) Providers and family representatives met on nearly a weekly basis during the legislative session developing a coordinated plan of action for lobbying the legislature. This persistent and unified effort was probably the greatest reason for the successful passage of these two bills.

Materials Reviewed

Covert, Susan, Survey of Family Support Needs in New Hampshire, Institute on Disability, October 1988.

For the Love of Our Families, for the Sake of Us All, A Report on Support Services for Families Who Have Member with Developmental Disabilities, N.H. Family Support Task Force, December 1988.

NH Law RSA 171-A; NH Law Chapter 255, Act Establishing a Family Support Network.

Family Support A Final Report: Two Granite State Model Programs, N.H. Department of Health and Human Services, June 30,1989.

Correspondence from Dan Van Kuren, Division of Developmental Services, re Medicaid Issues.

NEW JERSEY

Name of Program: Family supports in New Jersey are not listed as a separate program.

Nature of Program: Some supports to familes provided through regular community services.

Date of Implementation:

Administering Agency/Contact Person: Division of Developmental Disabilities. Contact: Robert Nicholas, Director, 609-292-3742.

Type of Program: Services

Number of Families Served: This was unknown, as family support is not defined as a program. Monies used for community services are pooled and can be used for everything from group homes to family care.

Eligibility Criteria: The federal definition for developmental disabilities is used to determine eligibility. For children in early childhood, they must be labelled with at least two "deficits" in development to receive services. Diagnostic categories are not the sole criteria for eligibility; a person's ability to function in the community is also an important consideration.

Services Covered/Allowable Expenditures: Case management, respite, some assisted devices.

Limit on Benefits to Individual Family:

Current Funding Level: Estimated at $8,793,000.

Background: More than 15 years ago, the State of New Jersey moved from institutional placement to more community-based options (group homes). As children moved into adulthood, they found inadequate options for services in the community both in terms of places and dollars. This combination led the state to look to the family as a major support and resource. In the last 5-6 years this focus on the family has intensified.

With the passage of the Division of Developmental Disabilities Act in 1985 the number of people eligible for services increased but the available resources did not.

Since 1985, the DD council has been committed to respite and has awarded service grants to 13 agencies to begin to develop a support network with the objective of keeping families together.

By 1987, the number of agencies had grown to 18 serving more than 360 families statewide. The same private agencies continued to receive funding during 1988. Total state and federal funds for this project have come to $1,435,216 with the state having taken over a good deal of the support for the program this past year.

Program Structure: Goals for services in the state are not specifically related to families but rather are stated as over-all goals: To provide services to persons in the community.

First contacts with the system are through the assignment of a case manager. The division operates a statewide information and referral network; individuals are also referred directly through local agencies. Parents then make the contact directly with the agency. They are assigned a case manager who assists them in working out what services they need and how to obtain them.

Under state regulations, an Individualized Habilitation Plan is written specifying what services will be received. The degree of family participation varies, but there are efforts to include families in the process. Given the lack of resources available, families often do not receive needed services.

The respite component in the state serves only an estimated 5% of the statewide need for in-home respite care. Respite workers must be trained in a variety of areas and the availability of the service is dependent on those agencies that receive funds from the Developmental Disabilities Council for respite services.

Other components of the system provide case management (which is available to everyone in the system), homemaker services, and engineering devices for home adaptation.

Implementation Issues: Eligibility is determined through acquiring a developmental disability label. It is also based on information from the parents and case managers. Priority is given to families in which: 1) an individual is labelled severely developmentally disabled and at risk of being institutionalized; 2) a child is unable to participate in day programs due to the nature or severity of their disability; and 3) there are aged or single parents.

After the passage of the Division of Developmental Disabilities Act, an assessment was developed to measure functional ability. A critical adaptive behavior inventory was developed and is used statewide for adults and the Vineland Adaptive Behavior Scale is used to determine over-all eligibility for children.

New Jersey presently has a waiting list for at least 2,000 people for services, the majority of that number being adults.

Planning for services on the state level includes people with disabilities and parents, but their involvement is limited. A wider advisory group might be beneficial to both the families and the department planning future directions.

Medicaid Policy: The State of New Jersey uses a number of different waivers. People who do not receive anything from a state agency but are eligible for Medicaid have a variety of different waivered programs, although the bulk of the waivers target the elderly population.

There is also use of Social Services Block Grant Program (Title XX) which offers counseling, homemaker services, information, case management, and other services for targeted populations. For further information on Medicaid and waivers, Contact: Danuta Buzdygan, New Jersey Department of Human Services, 609-388-2718.

Related Efforts: In New Jersey, agencies which comprise the public service network, though working as independent entities, all include developmentally disabled persons as part of their target population, and all provide some needed services to selected segments of the developmentally disabled population.

Education. Main support to parents with school-age children. Also, P.L. 99-457 is being implemented in this department.

Health. Provides case management to families with children 0-18 who have critical health needs. Children with AIDS are included. The program and agencies funded by it use a sliding fee scale. Contact: Barbara Kern, Special Child Health Services, 609-292-5676.

Statewide Computerized Referral-Information Program (SCRIP). This is funded through the state Developmental Disabilities Council to provide information and referral services to developmentally disabled persons in New Jersey. (800) 792-8858 inside New Jersey, (609) 292-3745 outside New Jersey.

Evaluation: Services in New Jersey focus on a broad range of people. The state does provide a respite program which is highly regarded by families. Opportunities to receive respite are, however, very limited.

The need to address family supports arose from a lack of services for people within the regular system of services. New Jersey is currently affirming the family as a major resource and an alternative to erecting a system of services outside the family unit.

There seems to be little long term planning related to supporting families. Though there are some pilots, they are very limited. Efforts at this time, appear to be focused particularly on adults.

Future Direction: More planning and funding are needed; those needs must be communicated to the legislature. The term "family supports" should be more clearly defined both by people working in the field and by families.

Lessons Learned: Encouragement of strong consumer involvement and allowance for flexibility are key guiding principles for family support.

Materials Reviewed

Certain Unalienable Rights, the Final Report of the Governor's Task Force on Services for Disabled Persons, April, 1987.

Hands On, Final Report on Project Redirection, 1988.

INTERFACE, Respite, New Jersey Developmental Disabilities Council, September/October 1986.

The New Jersey Developmental Disabilities Council, Annual Report, 1988.

New Jersey State Plan for Services to Persons with Developmental Disabilities, 1987-1989.

Project Redirection Implementation Plan: Stage I, A Project of the University Affiliated UMDNJ-Robert Wood Johnson Medical School in Cooperation with the New Jersey Developmental Disabilities Council and the Division of Developmental Disabilities, New Jersey Department of Human Services, June 1986.

NEW MEXICO

Name of Program: Respite Care Program

Nature of Program: Pilot

Date of Implementation: 1986 or 1987

Administering Agency/Contact Person: Department of Mental Retardation and Developmental Disabilities. For information about family support efforts in New Mexico contact the State Developmental Disabilities Planning Council, Room N3050, P.O. Box 968, Santa Fe, NM, 87504-0968

Type of Program: Services

Number of Families Served: Number unknown

Eligibility Criteria: There are no eligibility criteria aside from a label of developmental disability.

Services Covered: Respite

Limit on Benefits to Individual Family: Funded on a unit cost basis.

Current Funding Level: $187,000

Background: Efforts related to family supports are very limited in the State of New Mexico. The main source of supports to families comes in the respite program through the Department of Mental Retardation and Developmental Disabilities. The Developmental Disabilities Council has sponsored a variety of different respite programs, which were typically not seen as necessary in the state. A pilot program which trained parents to organize around the issues of family supports was implemented by the Council. In the three years of funding, this pilot worked to train sitters and parents to train and set up services. They are now using it as a model for other programs. The pilot will be completed up in September of 1989 and from that they hope to gain stronger support. There is presently a committee looking into further funding for continuation of the efforts.

Presently, the only family supports being offered beyond the respite efforts are available to foster and adoptive families in the form of financial reimbursement.

Program Structure: The overall goals of the program in New Mexico are to keep children out of institutional placements and support families in doing so.

There has been advertising among some local communities in local newspapers and through flyers making families aware of the respite services.

All the money allocated for respite services is contracted to individual community providers who apply for respite dollars in their contracts submitted to the Developmental Disabilities Bureau. Assistance is typically for a short period of time and generally has been limited to families that are in crisis situations.

Implementation Issues: The only eligibility criteria appear to be a label of developmental disability. Community agencies seem to be the decision-makers regarding who receives the service; this varies depending on their individual criteria. There is no data on the number of people waiting to receive respite services.

Interagency cooperation is beginning in the state, and there is a growing awareness of a need to increase of parental involvement in determining needs. A task force including a broad range of participants has convened and has produced a report on the needs related to families.

Medicaid Policy: There is presently talk in the state of expanding the Medicaid waiver to develop some specific services that would assist families, but there is a reluctance to expand. Contact: Patty Ikard (parent now serving as part time Executive Director for community providers and involved in task force looking at Medicaid waiver issues) 1820 Muscatel, Carlsbad, NM 88220, 505-884-2363

Related Efforts

Health/Maternal and Child Health. This department is providing some supports to medically-fragile children as well as some nutrition programs.

They also have some **SPRANS (Special Projects of Regional and National Significance)** grants which are federal grants created to provide alternatives to lengthy hospital stays for children who require medically complex care. Contact: Ann Taulbee, Maternal Child Health, 505-827-2350

Department of Human Services. They handle money for all Medicaid and will implement any family supports in the future.

Parents Reaching Out (PRO). Information and contact for parents related to efforts in the state. Contact: Leu Phillips, Parents Reaching Out, 1127 University, N.E., Albuquerque, NM 87102, 1-800-5176.

Evaluation: Efforts in the State of New Mexico are very limited, yet beginning. A strong coalition of parents is taking on a great deal of responsibility for establishing family supports in the state.

Parents at this time have little or no flexibility in terms of the respite program or of services in general. More financial support, for example, goes to foster and adoptive parents than it does to natural parents.

It does appear, however, that the Developmental Disabilities Bureau is becoming receptive to the need for a change. A new director is setting directions for the future.

Because of the present economic status of the state (suffering from problems with the oil industry), it is doubtful that additional funds will be provided for additional services.

Future Directions: The increase in family supports in the State of New Mexico seems imminent. Parent groups have emerged around the issue of family supports. A report has recently been issued by a task force looking at the needs of families, it suggested the developmental of additional pilot projects in the state, including cash assistance.

Lessons Learned: There is a need to build a strong base of support to plan and create family supports, as well as to build support within the legislature. It is important that planning domains be established that include people from different departments who support the idea of moving toward increased family support.

Materials: None sent.

NEW YORK

Name of Program: Family Support Services

Nature of Program: Began as demonstration project, has been permanent part of Office of Mental Retardation and Developmental Disabilities (OMRDD) budget for past four years, and prior to that it was a demonstration project.

Date of Implementation: FY 1984-85

Administering Agency/Contact Person: The Office of Mental Retardation and Developmental Disabilities (OMRDD), Andrew Ulitsky, Director (or Mary Ellen Giblin), Bureau of Program Design, 44 Holland Avenue, Albany, NY 12229, 518-473-6062.

Type of Program: Comprehensive service delivery.

Number of Families Served: Approximately 24,000 families are served in this program.

Eligibility Criteria: Presence of a developmental disability. All ages are served with the bulk being in the 6-17 year range. There are no restrictions based on to income level.

Services Covered/Allowable Expenditures: The program takes an "anything goes" stance which provides for 25 services including respite, transportation, recreation, advocacy, behavior management, and financial assistance. The state also sees family support services as filling any gaps in service, especially in the area of crisis intervention. Services are offered through more than 450 private programs financed through the Office of Mental Retardation and Developmental Disabilities. Allocations are broken into the following percentages. Day/evening respite 35%; Overnight respite 30%; Leisure/recreation, 9%; Transportation, 8%; other, 18%.

Limit on Benefits to Individual Families: Average of $1,000 a year per family.

Current Funding Level: $22.5

Background: The New York Family Support Services program began five years ago as a demonstration project, with approximately $300,000 initially allocated to provide for services that would meet family needs. Over that five year span, the program's budget has increased to $22.5 million and serves approximately 24,000 families. A voucher program has also begun in several areas this past year in which money will be given to 3 service agencies to provide vouchers for families to purchase services for their disabled family members. The state also has added Crisis Intervention and Free Standing Respite Programs which provide support to families in crisis as well as overnight and day time respite services outside of the home. Funds last year were also targeted to minority groups, people labelled medically fragile and those on extensive waiting lists for service.

Program Structure: The Office of Mental Retardation and Developmental Disabilities sends out Request For Proposals (RFPs) on an annual basis with the intention of working through private providers. They presently have 477 small contracts which offer a range of 25 services. Requests for Proposals require a brief two-page proposal; the only restriction is that only 15% can be devoted to administrative needs. If an agency is funded, and quality of services approved, there is no need to apply annually. Administration of the program comes through 20 local offices, and program entry comes at a local level. An intake person establishes with the family their particular needs and the local agency in turn, provides the services.

The program's initial goals were to keep families together and to delay or prevent institutionalization.

The program was publicized on a statewide basis as well as in local areas. Forums have been held throughout the state which focus on the future of the Family Support Services Program. The majority of those involved have been families using or hoping to use the services as well as local government agencies, legislative staff and private providers.

The state presently has no appeal process for families if they are rejected from services, and is aware that a number of families (approximately 65,000) will not receive services because supply is much less than the growing demand.

Quality control issues are handled by the agency responsible for providing the services. Each agency does its own self-evaluation, and the local Offices of Mental Retardation and Developmental Disabilities does monitoring to maintain control at the local level.

Implementation Issues: Virtually any family with a member labelled developmental disabled is eligible for service. There are no age or income criteria. Families actually receiving services are determined at a local level, as are the exact services that the family will obtain. Initially, the state had required local agencies, local government and families to contribute some money, but this was not well received and was withdrawn. The state estimates that there are 90,000 families that need services and 24,000 that are being provided with services. At this time it is estimated some 75% of all developmentally disabled people in New York State live at home. Nearly two-thirds, 64%, have a household income below the $20,000 median of all families in the nation. There has been a concerted effort to inform families of the availability of services from the onset which invited a deluge of applications.

There have been some state efforts at interagency cooperation but the focus remains at the local level. The Council on Children and Families has tried to bring people together on an informal basis, but task forces are not promoted. Local efforts have proven very productive. In 1990-91, OMRDD is planning to implement a comprehensive array of services project in one large county. Funding for a variety of family needs would be pooled from all agencies involved.

Medicaid Policy: Medicaid funding is not used for the Family Support Services at this time. There is concern that it would restrain and hamper the programs flexibility. There is also concern about stigma ("welfare") that might be associated with Medicaid funding. The state has considered looking at waiver alternatives. Recent changes in state law, however, will allow Medicaid services for 400 children labelled developmentally disabled and having complex health care needs who would otherwise be ineligible for Medicaid. As part of a waiver program, parental income and assets can be disregarded in establishing eligibility for children living at home. For further information on Medicaid policy in New York state, contact: Linda Reese, Social Services Home Care Coordination, 518-473-5491.

Related Efforts: Other departments that may have some programs related to family supports are:

Department of Education. For information, call 518-474-5548.

Department of Mental Health. Contact: Mary Armstrong, 518-474-8394.

Department of Health, Bureau of Childrens Services. Contact: Monica Meyer, Director (518) 474-2084.

Physically Handicapped Children Program. Contact: Bud Milner, Director, (518) 474-2084.

Department of Social Services. Contact: Linda Reese, Care at Home Coordinator, (518) 473-5491.

Office of the Advocate for the Disabled. Contact: Julia Schecter, (518) 473-4129.

Evaluation: The family support program in the State of New York is one that has grown rapidly in a relatively short period of time, although the numbers of families receiving services remain relatively small. There appears to be a strong impetus toward local community-based control of funds.

Services in most cases are agency-based, yet there is a strong effort to identify and pursue alternatives to existing programs. This has been generated by forums and other attempts to organize local consumers. The forums have also been an excellent way to hear from people directly affected by the program.

A challenge remains in relation to the development of the autonomy and flexibility that are central to the program philosophy. A strong commitment exists to examine cash subsidies, voucher programs, and other innovative approaches that increase family control.

Future Directions: A major concern for the future of the program is the issue of flexibility. Flexibility is emphasized by providers, parents and administrators. The state has been looking at a variety of options for increasing the flexibility of services such as vouchers and cash subsidies, as well as alternative funding sources (waiver program, Medicaid, etc.).

There is a need for additional services such as increased respite, transportation, home-care services, crisis intervention options and training to adress the needs of individuals with behavior challenges. The state will need to look more closely at who is not being served and making services available to all groups in all areas of the state. The commitment is to move gradually toward making family supports a major source of services.

The state continues to question whether family support provisions do, in fact, defer institutionalization or out-of-home placement.

Lessons Learned: Looking at specific needs of the people that are being served has been very useful in the state for determining how to plan for support to families. Parents have expressed high levels of satisfaction and the program has stimulated new providers to become involved in family support initiatives.

As the Office of Mental Retardation and Developmental Disabilities has experienced some decentralization of services and has become more attuned to the community, they have received the potential for greater flexibility in services.

Constraints should be minimized as much as possible, and regulations should remain flexible. It is important to demonstrate what works before policies are set. Listening and learning from families is key, as is remaining open to new approaches and models.

NORTH CAROLINA

Name of Program: North Carolina does not have a family support program.

Nature of Program: Some services to families through programs within the community services budget.

Date of Implementation: Services started in the mid-to-late 70's.

Administering Agency/Contact Person: Department of Human Resources, Division of Mental Health, Developmental Disabilities, and Substance Abuse (DMHDDSA), Barbara Harris, Chief of Support Services,(919) 733-3654.

Type of Program: Direct services, primarily respite care, are provided to families.

Number of Families Served: 1700 individuals received respite care. This figure represents a duplicated count of services received.

Eligibility Criteria: The respite care program has no age or income limitations. Some respite care is offered on a sliding fee scale. Persons eligible for respite care must have a developmental disability by federal definitions. Additionally persons with mild mental retardation and persons with head injuries are included.

Services Covered/Allowable Expenditures: Day services, Residential services, and Support services (respite).

Limit on Benefit to Individual Family: Respite care is provided based on need.

Current Funding Level: FY 88-89: $812,311 in state money; $175,500 in federal money for 4 demonstration projects offering additional respite care.

Background: North Carolina does not have a family support system as such. The DMHDDSA offers a traditional set of community based services. However, these services are provided for individuals in a variety of settings such as group homes and residential care facilities and not exclusively for individuals living in their natural homes.

Respite care is one of the oldest services offered by the state. This service most nearly matches the definition of family supports. The development of respite care was organized in the mid 70's by the Associations for Retarded Citizens. They received funding for the early respite care programs. The development of respite care also led to the growth of other community services. In several other states, respite care and community services grew as a result of deinstitutionalization. In North Carolina the onset of these services started prior to the deinstitutionalization movement.

The goals of the support services are: To provide relief to the family in their care giving responsibilities, to provide family support, and to provide temporary care for the member with the disability.

Program Structure: There are 41 service areas/programs which cover 100 counties in the state. While the program is intended to be state wide, the services are variable and in some areas respite care is unavailable.

Respite care in North Carolina has five different service models: 1) center based respite care: provides up to 30 days of residential care for 3-6 persons; 2) in-home/companion/sitter care is provided in person's home and can be used for overnight care; 3) private home respite care is provided in care giver's home, usually for overnights; 4) drop-in center care is provided for a couple of hours at a time, usually during the day; and 5) extend-a-family reimbursements are made to friends or relatives who provide the respite care.

The respite care provided independently by the 41 service areas, is flexible in terms of eligibility criteria but restrictive in terms of availability and hour limitations.

Implementation Issues: The state of North Carolina has 41 programs, each operating under different circumstances. To that extent there is little coordination or uniformity. Respite care is provided on a sliding fee scale and here too, the criteria and participation rates are decided by the service provider. Every respite program must have an appeal mechanism but it is unclear how grievances are resolved. Finally, not all of the service models are available in every program area which leaves a family with limited choices.

Medicaid Policy: The state of North Carolina has a title XIX Medicaid waiver program, Community Alternative Program (CAP). This program serves 550 people with mental retardation and covers goods and services such as, case management services, personal habilitation, durable medical equipment, respite care, personal care, homemaker services, and home mobility aides. The respite care provided under the Medicaid waiver is in addition to the respite care provided under the state's support services. The contact person for the Medicaid waiver is Barbara Harris, (919) 733-3654.

Related Efforts

Much energy is being directed toward interagency cooperation and communication. The state has a task force for chronically ill children involving numerous agencies. An interagency agreement exists between the **Division of Health Services for Children** and the **DMHDDSA** to exchange information and develop service coordination. Additionally, a case management system is being developed to provide a smoother transition from program to program. These activities will enable the Divisions to pool their resources and provide continuity of care.

The Department of Education. This department is responsible for the special education of 3-5 yr. olds. The contact person is Kathy Nesbitt, (919) 733-3004.

The Department of Human Resources. This is the lead agency for the 0-2 services under PL 99-457. Kim Lake is the contact person for the program. It is a joint position with the DD Council which is housed in the Department of Human Resources. The number is (919) 733- 3654.

The Department of Maternal and Child Health. This agency has several programs for families and children. **Baby Love** is a parent training program promoting healthy parenting and well-child care. The Department also offers an injury prevention program. A multi-evaluation diagnostic team provides early identification for children at risk. Other services provided by the Department include an adaptive equipment program, medical care, and genetic counseling. The contact person for the Department is Tom Vitaglione, (919) 733-7437.

Evaluation: Each non profit provider of service must meet certain criteria to contract with the state. The DD Council did an evaluation of the programs and no major problems were noted.

Parents have some role in the planning and developing of services. An opportunity to expand the role exists but it is not being fully exercised. The DD Council provides training and advocacy to parents and professionals involved with obtaining services and other consumer issues. There is good parent representation on the PL 99-457 planning board.

Finally, the MR/DD specialists at the local levels are fairly visible North Carolina has a Family Support toll free number, 1-800-TLC-0042.

Future Directions: North Carolina does not have a recognized family support program. However activities at various levels are aimed at supporting families in their role of caring for members with special needs. An emphasis on family support is just beginning to take place. The Governor has formed a commission to address family issues .

Lessons Learned: A family support program needs the support of a variety of consumer organizations. They need to coalesce around similar issues to provide a broader constituency. Second, collaboration among state agencies is important to pool resources and avoid duplication of efforts. Finally, and most importantly, parents must be involved in all matters concerning family supports.

Supporting material: none

NORTH DAKOTA

Name of Program: 1) Infant Development Programs, 2) Statewide Respite Care Services, and 3) Family Subsidy Program.

Nature of Program: Ongoing state funded programs which are administered regionally by the Developmental Disabilities Case Management System.

Date of Implementation: Enabling legislation for the Family Subsidy Program passed in 1979. In 1989 the state legislature passed new appropriations for Family Support Services.

Administering Agency/Contact Person: Mary Beth Wilson, Family Support Services, Division of Developmental Disabilities, Department of Human Services, State Capitol Building, Bismark, ND 58505, (701) 224-2768.

Type of Program: 1) The Infant Development Program provides home-based transdisciplinary services, including parent training, to children birth to 3 and their families; 2) Statewide Respite Care provides basic respite care services, extended respite care and respite care level II (trained health care professionals) 3) Family Subsidy Program provides up to $35 per week to families with a child with disabilities living at home; and 4) It is proposed that Family Support Services will fund in home support for families, case management services, relief care, and skill training to enable the person with disabilities to live more independently within the family home.

Number of Families Served: In FY 1988: 1) Infant Development Program: 272 individuals were enrolled; 2) Respite Care: 314 persons; 3) Family Subsidy Program: 198 families; 4) Family Support Services: 290 families are anticipated to participate in this program on a monthly basis.

Eligibility Criteria: 1) Infant Development Program: This program is open to children birth to three with significant delay in at least two developmental areas 2) Respite Care: Assistance is available on sliding scale to families caring for a family member with a developmental disability; 3) The Family Subsidy Program provides financial assistance to parents (natural, adoptive, or legal guardians) caring for a child, under the age of 21, who is developmentally disabled. The family must demonstrate a financial need to participate in the program; 4) Family Support Services are available to families caring for a family member with developmental disabilities (this program may include families who have an adult family member).

Services Covered/Allowable Expenditures: 1) Family Subsidy Program provides minimal cash assistance to reimburse families for "excess costs" (up to $35 per week) for services which can include, but are not limited to the following: 1) purchase of special equipment, 2) specialized therapies, 3) special diets, 4) medical or dental care not otherwise covered, 5) home health care, 6) counseling for child or family, 7) respite care, 8) special clothing, 9) educational programs not provided by the public schools, 10) child care, 11) recreational services, 12) transportation, 13) housing rehabilitation, and 14) excess cost of health insurance.

2) Funding for Family Support Services can be used to provide relief care and in-home training, but cannot be used to purchase equipment or make home adaptations.

Limit on Benefits to Individual Families: For families enrolled in the Subsidy Program, financial assistance cannot exceed $35 per week and must be used for services or treatment which the child receives in accordance with the individual habilitation plan.

There is a sliding fee scale for current respite care services.

Current Funding Level: The North Dakota Legislature cut the Family Subsidy Program from $572,000 for last biennium to $300,000 for the current biennium. They did appropriate, however, $3,677,000 in new dollars for Family Support Services.

Background: Since 1981, in a decision coming out of a lawsuit against the state institution, North Dakota has been under a Federal court order to improve services. This court order has provided the impetus to increase developmental services at the community level.

Program Structure: North Dakota's developmental services are administered through eight Regional Human Services Centers. To receive family support services or the family subsidy, a case manager and service team must develop a individual habilitation plan with the family outlining specifically what support services the family will receive and what costs the family subsidy will cover. Much of the support to families through this new program will be provided by support services staff coming into the family's home to provide training to the family and instruction to the person who is disabled. Families found ineligible for services have a right to an appeal through administrative hearings or through more formal legal due process.

At the individual level, case managers monitor services and gage quality assurance. Service providers must be licensed through the Department of Human Services and accredited by the National Accreditation Council for Services to Individuals with Developmental Disabilities. In addition, the state has an active Protection and Advocacy Project and is followed by the Federal Court Monitor.

Implementation Issues: Too soon to know for Family Support Services.

While the state does have an Interagency Coordinating Council through the Part H Grant, there are no formalized agreements between North Dakota's various departments serving children and families.

Medicaid Policy: Medicaid dollars, through Title XIX Waiver will fund $993,000 of the $3,677,000 North Dakota has allocated for family support services in the current biennium. Contact person for Medicaid is Michael Haring, Administration, Policy Analysis, Planning, and Coordination Unit, Developmental Disabilities Division, Department of Human Services, State Capitol Building, Bismark, ND 58505, (701) 224-2768.

Related Efforts: Through PL 99-457, North Dakota has an interagency coordinating council examining issues affecting children 0-3 and their families. Contact person for this activity is: Robert Graham, Division of Developmental Disabilities, Department of Human Services, State Capitol Building, Bismark, ND 58505, (701) 224-2768.

Evaluation: The state Division of Developmental Disabilities has accepted the premise that no parent because of a lack of resources or services should be forced to institutionalize their child; the creation and funding of the Family Support Services indicates the state's commitment to families. It is too soon to know whether the method of family support adopted by North Dakota will be able to adequately and effectively address families' needs.

As is true nationally, services are sorely lacking for North Dakota families who have family members with disabilities other than developmental disabilities.

Future Directions: In the coming year the state will be evaluating the efforts of its newly funded Family Support Program.

Lessons Learned: North Dakota reports that from a legislative standpoint, they have found it easier to develop and fund services for children than for adults. They advise states considering family support services to offer these services early to families, preventing the need for greater and more costly services later. Support should be highly individualized and flexible enough to meet family needs.

Material Reviewed

Developmental Disabilities Chapter 75-04-04, Family Subsidy Program Regulations.

OHIO

Name of Program: Family Resource Services

Nature of Program: The program was established byan act of the Ohio legislature.

Date of Implementation: July 1984

Administering Agency/Contact Person: Ann Hinkle, Family Resource Services, Ohio Department of Mental Retardation and Developmental Disabilities, 30 East Broad, Columbus, Ohio 43215, (614) 644-7342.

Type of Program: Family Resource Services provides reimbursement or vouchers to families for all or part of the expenditures incurred in meeting the special needs of a family member with mental retardation or other substantial developmental disability.

Number of Families Served: Approximately 4,646 families were served in the third quarter of FY 1989 and 3,939 families in the fourth quarter of the same year .

Eligibility Criteria: Families or guardians of an individual who has mental retardation or other substantial developmental disability.

Services Covered/Allowable Expenditures: Family Resource Services can be used to pay for: 1) respite care; 2) counseling, training, and education for members of the family that aid the family in providing proper care for their family member with disabilities; and 3) special diets, purchase or lease of special equipment, or home modifications needed to improve the living environment or to facilitate the care of the individual.

Limit on Benefits to Individual Families: The maximum level for reimbursement is $2,500 annually. If a family's taxable income exceeds $15,000, families are required to make a co-payment on a sliding scale for services. Families with an income of over $78,000 are not eligible for services. Under extenuating circumstances, families may receive more than $2,500 reimbursement, but this amount may not be more than 50% of the average annual cost of services to a resident of a development center.

Current Funding Level: Allocations for Family Resource Services are $4,638,160 for FY 1989/90 and $4,777,305 for FY 1990/91.

Program Structure: The stated purpose of the Family Resource Services program is to promote the unity of the family by assisting them to meet the special needs of their family member who has mental retardation or other substantial developmental disabilities. The program is designed to assist the individual to be more self sufficient and to prevent or reduce institutionalization. The program is directed by the Ohio State Department of Mental Retardation and Developmental Disabilities and administered at the local level by County Boards of Mental Retardation and Developmental Disabilities, or their contract agencies. Each County Boards must have at least two parents represented on their board of directors.

Upon application for Family Resource Services, County Boards: 1) Determine the appropriateness of services requested by the family (will they improve the living environment or facilitate the care of the family member who is disabled); 2) identify other resources available to the family to pay for support services; 3) determine that the family has exhausted all other sources; and 4) establish the family's share of the service cost, if any. Families may request a provider list from the County Board or select their own providers; a family selected provider must be approved by the County Board. It is permissible for families to use relatives as respite care providers.

Implementation Issues: The amount and type of services available to families are determined annually by counties in their comprehensive service plans, which must be approved by the state. Not all possible family resource services (see Services Covered Section) may be available in every county. Last year 770 Ohio families requesting Family Resource Services were denied services (reasons for service denial vary; it would be interesting to know how many of these families did not receive services because they were unavailable in their county). Case management is one component of Ohio's developmental service system; the case load is 100 clients. The state has a formal and well-established method for service coordination for individuals with multiple problems (see Interdepartmental Cluster, Related Efforts Section).

Medicaid Policy: Ohio has two Model Waivers, Alpha and Open Doors. Alpha assists families providing home care for an individual who requires the level of care provided in an Intermediate Care Facility. The Alpha Waiver is intended to serve 200 individuals; the Waiver designates that of these 200, twenty be individuals who are technology-dependent. Services covered through the waiver include: case management, home modifications, supplies, habilitation services, homemaker services, personal care, transportation, and respite. The Open Doors Waiver is designed specifically to enable 40 individuals residing at the Hattie Larlham Foundation, or other ICF-MR facilities, to move into foster settings. The state has two regular waivers: Passport, which serves individuals who are elderly and/or disabled and require ICF or SNF level of care; and the Aids Waiver, serving individuals with Aids or Aids Related Complex who would otherwise be hospitalized. For more information contact: Eileen Figge or Kim Fahrney, Ohio Department of Human Services, Division of Long Term Care, (614) 466-6742.

In addition, the state's Department of Mental Retardation and Developmental Disabilities is planning to request two different statewide 2176 waivers: One for persons who are now living in intermediate care or skilled nursing facilities and another for persons who, with provision of services, can be deinstitutionalized or diverted from an ICF/MR. Medicaid-eligible persons who require ICF/MR levels of care and who live in a facility that meets Key Amendment provisions will be eligible for waiver services. This broad coverage will allow persons who live in almost any setting (excepting certified ICF/MR, ICF, SNF, and hospitals) to receive waivered services. This contrasts to the approved Ohio Model Waivers that limit participation to people who live with their own family or with a foster family. Covered waivered services will include: case management, homemaker, home health aide, personal care, habilitation, respite, transportation, adaptive equipment, and supplies. Additional services may be added as needs are evaluated. County Boards of Mental Retardation and Developmental Disabilities will administer the day to day operation of the waivers with oversight provided by the state Department of Mental Retardation and Developmental Disabilities. A group comprised of parents, and representatives from local providers, agency personnel, consumer and advocacy organizations, is assisting the Department in construction of these waivers. For more information contact: Linda Day, Ohio Department of Mental Retardation and Developmental Disabilities, (614) 466-7508.

Related Efforts

Ohio Curriculum Project. Ohio has developed this model for Early Intervention adopted throughout the state and replicated in other states. The curriculum, which was developed in 1983 with a Developmental Disabilities Planning Council grant, emphasizes 11 components of a comprehensive early intervention system, including: the necessity of genuine parent/professional partnerships, collaborative service coordination, comprehensive service delivery systems, and support to families from the beginning. As a result of the Ohio Curriculum Project, collaborative groups made up of parents and professionals have been established in all of Ohio's 88 counties. These collaboratives are working at the local levels to set priorities and develop resources to put in place the components of this early intervention curriculum.

Early Intervention Interagency Council. Ohio's efforts for implementation of PL 99-457 include the formation of this group, which is working to design a collaborative system of comprehensive services for young children, with or at risk of developmental disabilities, and their families. Through PL 99-457 grant funds, Ohio is establishing and expanding early intervention programs. Incentive grants are being awarded to counties statewide to develop effective models of intervention. One project includes the piloting of the **Prescribed Pediatric Extended Care** program for technology dependent and/or medically fragile children birth to five years of age. This program provides 12 hours a day of medical/development care to children that would otherwise be hospitalized, institutionalized, or isolated at home. For more information contact: Cindy Hirshfeld, Early Intervention Administrator, Ohio Department of Health Early Intervention Unit, 131 North High Street, Suite 411, Columbus, Ohio 43215, (614) 644-8389.

The Interdepartmental Cluster for Services to Youth. This agency was created in February 1984 by an executive order and later became part of Ohio statute. The Interdepartmental State Cluster requires the **Ohio**

Departments of Human Services, Mental Health, Mental Retardation and Developmental Disabilities, Youth Services, Health, and Education to work together towards the goals of strengthening families and keeping children in their own homes. The State Cluster is charged with addressing the program and policy issues affecting multi-need children and their families. **County Clusters** for multi-need children are mandated in all 88 Ohio counties. These interagency groups work at the local level to ensure that services are coordinated. County Clusters review individual cases of children with multiple needs and develop appropriate case plans for these children. When issues or individual cases cannot be resolved at the local level, referrals are made to the State Cluster. The State Cluster weekly reviews issues and specific cases regarding unmet needs of children with multiple problems. For more information contact: Mary Jane Frank, Cluster Coordinator, Department of Human Services, (614) 466-1213.

The Institute for Child Advocacy. This organization has established **Family Preservation Councils** in four counties. The councils are comprised of community leaders in human services, law, advocacy, child care, health, and education. The Councils are working to determine how new or existing resources can be used or re-directed in their own communities to keep families intact. These Councils are creating networks that cross traditional organizational and agency boundaries and developing creative and local solutions to problems confronting families. For more information contact: Gloria Mills, Institute for Child Advocacy, 3615 Superior Avenue, Building 31, Suite 2A, Cleveland, Ohio 44114, (216) 431-6070.

Evaluation: Family Resource Services have provided Ohio families caring for a family member with a developmental disability with services that are more individualized and family controlled than any previously available in the state. However, funding for this program remains inadequate and rules regarding support services do not allow for the degree of flexibility needed by many families. In addition, families whose family member has a disability other than a developmental disability appear to have few resources available to them.

Ohio has made significant strides in its efforts to better coordinate services and resources for children with disabilities and their families. The Interdepartmental Cluster model is worthy of replication. However, even with a strong commitment for interagency collaboration, a lack of resources means many of Ohio citizens with disabilities and their families remain unserved. A review of cases referred to the State Interdepartmental Cluster show a serious lack of community based services in many areas of the state. Too many Ohio children and youth are placed in residential services because a comprehensive system of community-based programs and services are not available. If the state is serious about reducing the number of out-of-home placements it must begin to redirect its resources to services which truly support families.

Future Directions: The Department of Mental Retardation and Developmental Disabilities believes Ohio's future efforts in providing family support will include greater agency collaboration, increased commitment of state dollars, a stronger Federal partnership in providing services, and increased responsiveness to individual family need. Ohio is currently involved with the Human Service Research Institute in a project to more closely examine the system of supports for Ohio families and to facilitate collaborative efforts in future planning. A Family Support Coalition has been formed by the Department of Mental Retardation and Developmental Disabilities to define the issues regarding support for families who have a member with a disability or chronic illness and to plan for the provision of coordinated supports.

In recognition that children and families often have multiple problems and needs, future plans for the State Interdepartmental Cluster include: 1) eliminating service gaps and avoiding duplicative efforts among state and local agencies; 2) plans to develop and provide increased family-based services with a focus on prevention and early intervention; 3) promotion of community and regional services that offer a continuum of care; 4) assisting County Clusters with training, technical assistance, and specialized consultant services; 5) helping County Clusters identify available funding sources; 6) obtaining feedback from County Clusters on current state policies/procedures/laws in order to make needed systems changes; 7) identifying and developing special treatment programs for low incidence populations (i.e. children who are dually diagnosed, autistic, violent, have eating disorders).

The Ohio FY 1990-91 biennium budget proposal contains over seven million dollars to create a Cluster line item. About three million dollars of this will address the needs presented by individual cases, four million is earmarked to provide incentives to local clusters to develop and/or coordinate programs and resources to better meet the needs of children and families at the local level. It is anticipated activities will include support for families of children with severe disabilities or complex health care needs.

Lessons Learned: Ohio's Interdepartmental Cluster appears to offer a good model for interagency collaboration and coordination that could be adapted by other states. Advice from the Department of Mental Retardation for state's interested in establishing family support is to start with families. Families need to be asked what they need and encouraged to look toward an ideal. It is crucial that professional not assume they know what is best for families.

Materials Reviewed

Family Resource Services Brochure.

Facts on Family Resource Services, Department of MR/DD.

Overview of Home and Community-Based Waivers, Department of Human Services, October 1988.

Ohio HSRI Technical Assistance Proposal.

State of Ohio regulations for Family Resource Services.

Implementing PL 99-457 in Ohio, Department of Health, Early Intervention Unit, December, 1987.

Clustering in Ohio, Department of Human Services.

OKLAHOMA

Name of Program: There is no family suport program in the state, however some people are supported in family homes under the Home-Based Medicaid Waiver

Date of Implementation: 1983

Administering Agency/Contact Person: Department of Human Services. For further information about the development of family supports in Oklahoma contact Oklahoma Planning Council on DD, Room 307, P.O. Box 25352, Oklahoma City, OK, 73125

Type of Program: Services

Number of Families Served: 350 individuals in Hissom case were mandated plus additional through application for waivered services.

Eligibility Criteria: People determined to be mentally retarded, who meet financial eligibility requirements of the Oklahoma Medicaid program, people who receive institutional care (ICF) or would require institutional care in the absence of home and community-based services under the waiver. Services under the waiver address only individuals that are 6 years of age or above.

Services Covered/Allowable Expenditures: Habilitation services, specialized foster care, homemaker services, respite care, professional assessment teams and case management.

Limit on Benefits to Individual Family: NA

Current Funding Level: The average per capita fiscal year expenditures under the waiver will not exceed the average per capita expenditures for the level of care provided in an ICF-MR under the state plan.

Background: In 1983, the Oklahoma Commission for Human Services adopted the position that wherever possible, services should be provided in the community rather than in large institutions. The Division of Developmental Disability Services conducted a needs assessment which indicated unmet needs for services to mentally retarded citizens in the state. Under the state's waiver request, only people in ICFs or in the community who in the absence of the waiver would need or continue to need institutional care would be eligible for home and community-based services. Six people were designated to be served the first year, with a total of 938 by the third year.

Beginning in 1988, the state requested a waiver for home and community-based services for people labeled mentally retarded who would otherwise require the type of care as that give in an ICF. Services are limited to 600 in the first year, 750 in the second year, and 938 in the third. Limits are presented because of the state's ability to recruit, train and monitor services.

The initial waiver received in 1985 was re-submitted and approved in May of 1988. In June of 1989 the waiver was amended to streamline the assessment process. Plans are to include another amendment request which would broaden family supports to include adaptive equipment and transportation, but this has not yet been passed.

Program Structure: After eligibility is determined, Individual Habilitation Plans (IHPs) are established which are to be individualized to the circumstances of the individual and are provided in the least restrictive environment consistent with freedom of choice, developed to ensure participation of those involved in the person's life. They are also monitored to reflect changes in the person's growth and provided within a system which recognized the person, parental and guardian's rights and responsibilities. A case management component is also in place to help locate, coordinate and monitor services.

Policy exists for client monitoring, which specifies the steps to be taken to assure services are delivered according to the person's individual needs.

On a quarterly basis, the supervisor of each case manager reviews the case records to determine if re-evaluation is required. Individuals using the home and community-based services are reviewed annually.

If not given the choice of home and community-based services as an alternative to ICF placement, a fair hearing may be requested. Upon completion of the initial evaluation, the intake team meets with the family and the individual to discuss findings and choices for services. In the standard format, the person is notified of their freedom of choice on institutional or home and community-based services, the freedom of choice among providers and the right to a fair hearing. Each plan must be reviewed by the court monitor.

The following waivered services are provided figure in parenthesis indicates average anuual cost of service: habilitation services ($10,974), employment services ($3,352), homemaker services ($5,310), specialized foster care ($8,960), and respite care ($900). People to be served under the waivered services comprise individuals who are institutionalized (designated as ICF-MR, private ICF-MR, ICF and SNF) as well as those in the community.

Medicaid Policy: As previously described, the State of Oklahoma is driven by Medicaid waivered services.

Related Efforts: There have been attempts to look at family supports in the following departments in the State of Oklahoma:

Department of Education. Connie Siler, Director of Special Education or Earline Bellings, 405-521-3351.

Department of Mental Health. There is an adolescent support group as well as family support group, no contact given.

Department of Health. There has been a family support grant for 4-5 years as well as parent support groups that have been developed. Dr. Ed Rhodes, Director of Pediatric Services, 405-271-4471 or Dr. Sara Depercio for information on Maternal and Child Health and programs in that area at the above number.

Oklahoma Planning Council on Developmental Disabilities. In related efforts this organization has sent out requests for proposals which would provide **Specialized Community Living Related Services** for individuals with developmental disabilities. Proposals can address integration and independence by conducting research related to strengthening family support services, assuring service availability, assuring service quality, providing solutions to barriers. The project will be for one year with the possibility for re-application for up to three years beginning in September 1989. For further information, contact Pat Burns, Executive Director, Oklahoma Planning Council on Developmental Disabilities, Will Rogers Building, Room 307, P.O. Box 25352, Oklahoma City, OK 73125, 405-521-4985.

Evaluation: Through extensive use of waivered services, there has been a major focus on community-based options for people with mental retardation. The system appears to have many drawbacks. Because of the concentration on the court mandate, there have been very few attempts to look at more individual ways to support families in the state. Under waivered services, children under 6 years of age receive no services. It appears that there is little flexibility within the state and little parental involvement; rather, the system is driven by a very systemic and rule-oriented structure. Parents of younger children, however, appear to be beginning to demand services in the community. There are efforts through public forums that are beginning to document family support needs throughout the state as well as the organization of a state advocacy group for parents.

Future Directions: Documentation of family support needs thorough forums as well as helping to promote state advocacy groups which would involve parents to a larger degree.

Lessons Learned: None indicated

Materials reviewed

Oklahoma Planning Council on Developmental Disabilities, Request for Proposal - Community Living.

State of Oklahoma, Waiver Application Services for the Mentally Retarded.

OREGON

Name of Program: Family Support Pilot Demonstration Programs

Nature of Program: Pilot

Date of Implementation: 1988

Administering Agency/Contact Person: Department of Mental Health, and locally administered through community mental health programs. Contact: Russ Gurley, Oregon Developmental Disabilities Council, 2575 Bittern Street, N.E., Salem, OR 97310-0520.

Type of Program: Specialized Support Services, financial assistance.

Number of Families Served: Approximately 75-85 families.

Eligibility Criteria: Persons who, in accordance with the state definition of developmental disabilities, are labeled such. The eligible person must live with their family or return to live with the family as a result of involvement in the program. There are no age, income or categorical disability criteria.

Services Covered/Allowable Expenditures: Services include, adaptive equipment and clothing, transportation, medical and dental services and supplies, home health and attendant care, special diets, home barrier removal, respite care, in-home training, recreational services, counseling services which may be directed to the person with the disability or the family.

Limit on Benefits to Individual Family: Arbitrary limits are not placed on families in relation to how much they can receive, as needs vary from family to family and change over time. An average of $5,000 a year is used as a budget guideline.

Current Funding Level: The state Developmental Disabilities Council allocated $364,000 over a two-year period and the state department of mental health allocated $246,000 from the state budget. For 1989-91, DD Council $364,000 and the state $522,000.

Background: Initiation of the pilot programs for family supports began in 1987 when legislation was part of the effort to get family supports in place. A parent study group was responsible for looking at what was happening in other states. In 1988, the Developmental Disabilities Council approached the Department of Mental Health with a plan for a four-year project which the Department agreed to participate in for two years. The family supports project is funded jointly by the DDC and DMH.

At this time, requests for proposals were sent out and three programs were chosen. All were part of the community mental health system. One is in an urban area, one in a rural and one in a urban/rural area. Dollar allocations were then established commensurate to population bases in each area. The pilot project began in 1988 and is due to operate through 1991.

Program Structure: The purposes of the family support pilots in Oregon are several: First, to meet the special needs of families who have exceptional caregiving requirements; to strengthen family capacities to provide care; to prevent unnecessary out-of-home placement; and finally, to make it possible for families to choose to have their family members return home.

Each area has a family support consultant who works with the family to assist them to determine their needs. That person will also help the family realize implications of receiving support through the program (e.g., if money is used to pay bills, it could affect families' welfare benefits). There are few restrictions at present related to what is obtainable. The consultant will make sure all other sources of assistance have been tapped before using family support monies. Families are then able to choose their providers.

Each community mental health center reviews applications and determines who will receive services. Families may receive funds in advance, and can pay for services themselves rather than to use a third party method. This helps the family to maintain independence and influence the quality of service they receive.

There is a waiting list at present, but the number on it is unknown. At this point, there is no formal quality control mechanism; however, each pilot program must provide information annually, related to families participating, waiting lists, and assessment of the impact of the program on families. An assessment of the extent to which the program is achieving its objectives and of the family and individuals satisfaction with the program is also completed.

In 1989, legislation was passed which may result in increased future funding.

Implementation Issues: Eligible participants are determined by the local community mental health programs. The person must be living with his/her family or return to live with the family as a result of participation in the program. The program has no restrictions related to age, family income or category of disability. Local mental health facilities are the entry point into the program.

Each pilot program forms a project advisory committee made up of parents, community mental health representatives, service providers and advocates who advise and make recommendations to the program on priorities for service. Each contractor is responsible for developing standards for priority consideration with input from its advisory committee and approval of the DD Council and Mental Health Division. This is based on judgments about the need for support. Families are assigned a family consultant who will assist them in all areas.

There are efforts in the State of Oregon at interagency collaboration related to the co-management of the service delivery system for children with developmental disabilities. Issues such as serving medically fragile children, pooling resources to serve children at risk for institutionalization as well as long range issues related to cross-training of local staff, information sharing and a number of other topics have been brought to the group's attention.

Medicaid Policy: In the area of developmental disabilities, there are currently no waivered programs. There may be a Katie Beckett waiver.

Related Efforts

Children and Youth Services. Contact: Linda Sundy, 503-373-1036.

Evaluation: One of the strengths of Oregon's family support programs is flexibility. The pilot phase promotes an atmosphere of openness and experimentation, unhampered by regulations. Families also exercise control over determining their own needs.

Each of the three pilots is focused on a different need area, which offers the state diverse data on needs in various regions of the state. It appears that in planning for the program, planners were very aware of the specific needs of their state and adapted models from other states to its unique aspects.

Future Directions: The program will be taken over by the state. Another important area of development is the continuing effort to organize parents.

Lessons Learned: Stress on the importance of studying what was available in other states and really looking at what the program offered beyond what was written on paper was very helpful in the state planning and implementation of the family support program. There are a lot of variables in each state and programs should be adapted to needs of the people they will serve.

Families were hesitant to accept what was offered to them, and would in some cases return money that they did not use.

Materials Reviewed

Connections, July 1989, Newsletter from the Program Office for Developmental Disabilities.

Oregon Developmental Disabilities Council, December 14, 1988, Information bulletin regarding questions regarding program funds.

Oregon Developmental Disabilities Council, Mental Health Division, Request for Proposals from counties and eligible organizations to develop a Pilot Family Support Program for the Families of Persons with Developmental Disabilities. 1988.

Senate Bill 522, 64th Oregon Legislative Assembly, 1987 Regular Session.

PENNSYLVANIA

Name of Program: Family Support Services

Nature of Program: Ongoing state funded services.

Date of Implementation: 1972 with revisions of the program in 1983 & 1987.

Administering Agency/Contact Person: Art Geisler, Office of Mental Retardation, Department of Public Welfare, P.O. Box 2675, Harrisburg, Pa. 17105-2675.

Type of Program: A Wide Range of Family Support Services

Number of Families Served: over 15,000 Pennsylvania families receive support services

Eligibility Criteria: Persons with mental retardation who live at home with biological or adoptive families, foster families, relatives, or legal guardians. Persons living independently in the community may also be eligible.

Services Covered/Allowable Expenditures: Family Support Services encompasses a wide range of services which include, but are not limited to: respite care, therapies, homemaker services, financial assistance, home modifications, parent training, recreational services, sitter/companion services, special diets, adaptive equipment, and behavior programming.

Limit on Benefits to Individual Families: Services are provided based on individual family need, available funding, and the county's ability to provide the service. Some support services (i.e. respite care, family aid, cash subsidy) have established service and monetary limits.

Current Funding Level: Approximately $12,000,000 for the 1989/90 fiscal year.

Background: The Family Resource Services Program was initiated in FY 1972-1973, making Pennsylvania the first state to provide statewide family support. In 1983, the Office of Mental Retardation opened up family support services to allow for greater programmatic and funding flexibility. In 1987/88 the Office of Mental Retardation introduced "family driven components" into their system; by the end of 1989 26 family driven projects, including cash subsidy and voucher programs, peer support, and grassroots organizing and planning efforts, will be in place in Pennsylvania.

Family support is now a well-established service for Pennsylvania families caring for a mentally retarded family member. In the past several years, there has been a move to make these support services less agency-controlled and more family-driven, with greater responsiveness and flexibility in meeting individual family needs.

Program Structure: Family Support Services are directed by the Office Mental Retardation in the state Department of Welfare and administered at the local level by the County Mental Health/Mental Retardation Program. The stated purpose of support services is to provide adequate resources within the community to enable families to maintain their family member with mental retardation at home with minimal disruption to the family unit and to enable the individual with mental retardation to lead as normal a life as possible with their family in a community setting.

The Family Support Service Subcommittee is an advisory body to the state Office of Mental Retardation. Most County Offices, but not all, have advisory boards with parent representatives. All the recently initiated, family-driven support projects are required to have family advisory committees.

Implementation Issues: Because the system is county controlled, with the County Programs responsible to the County Commissioners, there may be disparity in the quality and amount of family support across the state. Some counties are totally committed to family support and have funded a good system of service providers and developed community resources for families. For other counties family support may not be a high priority and the availability of these services is not widely known.

Medicaid Policy: Pennsylvania has recently received a 2176 Amendment to Medicaid which will be used to underwrite many family support services. Medicaid contact person is: Dana Olsen, (717) 783-5772.

Related Efforts

The Pennsylvania Developmental Disabilities Planning Council. This agency has funded four demonstration projects, two for families with children who are emotionally disturbed and two for families with children who have severe physical disabilities. These programs began in October 1987 and will run for through mid 1990. Families are provided with a variety of supports, including respite care and direct cash payments. The Council is working now to see what administrative and legislative policy changes should occur based upon the findings of these projects. For more information contact: Rosemary

Barrett, Developmental Disabilities Planning Council, 569 Forum Building, Harrisburg, Pa. 17120, (717) 787-6057.

The Office of Mental Health. In the past two years this office has initiated family support services; these have included: respite care, hotline services, day care, support groups, and financial assistance to bring a child home from an institution. Approximately 200 families have benefitted from these services. For more information contact: Carol Ward Colasante, Office of Mental Health, (717) 783-5132.

Evaluation: The quality of Pennsylvania's support services for families caring for a family member with retardation varies from county to county. Additional respite care and increased therapies are still needed by families statewide. In the past, services have been dictated by agency priorities and structure, rather than by families. With the advent of more family controlled programs this is beginning to change. A survey of those families participating in the family driven pilot projects show families have been extremely pleased with the services they have received. They reported a relief from the stress of caretaking, an ease of their financial burden, benefits from contact with other families, much appreciated time away, and satisfaction with the flexibility of the support.

As the state begins to use Medicaid dollars to fund support services, it will need to be careful to avoid passing Federal red tape and restrictions on to families. As one state official lamented when discussing the acceptance of Federal dollars, "The Feds bring so much baggage with so many hooks that everyone is miserable."

Services to families caring for a family member with a disability other than mental retardation are minimal. Perhaps the outcomes of the few pilot projects in the state will help to generate increased attention and funding for these families.

Future Directions: The Office of Mental Retardation plans to continue to make its system of services more responsive to individual families' needs. Through their pilot projects the state is attempting to give families more say in what services look like and how they should be delivered. In addition, the state office is conducting area wide public meetings to get direct input from families about the direction they would like to see family support take. The state hopes to see family support services more equitably distributed in the state with a better understanding at the local level of the efficacy of supporting families in their role as primary care giver.

Lessons Learned: Pennsylvania advises states wishing to develop support services to do it in the context of their geo-political environment and if at all possible, to have enabling legislation for family support services.

Materials Reviewed

Family Resource Services Regulations.

Office of Mental Retardation Bulletins amending these regulations, 1983 and 1984.

Pennsylvania Department of Public Welfare Mission Statement.

Human Services Research Institute Family Support State Summary, 1985.

RHODE ISLAND

Name of Program: Family Support Services

Nature of Program: A combination of legislatively mandated and budgeted supports

Date of Implementation: 1) In 1978 Rhode Island passed the Parent Deinstitutionalization Subsidy Aid Program; 2) Early Intervention Services were legislatively mandated in 1981; 3) In 1978 respite care was implemented; 4) In 1983 additional supports to families became available through the Medicaid Waiver; and 5) In 1989 the Rhode Island General Assembly passed an act establishing an Office of Family Support to provide services to families caring for adult family members with mental retardation.

Administering Agency/Contact Person: Patricia Zanella, Rhode Island Department of Mental Health, Retardation, and Hospitals, Division of Retardation and Developmental Disabilities (DOR/DD), 600 New London Avenue, Cranston, RI 02920, (401) 464-3235.

Type of Program: Services and financial assistance

Number of Families Served: In the last fiscal year: 1) 91 families received parent subsidy aid; 2) 703 families participated in early intervention services; 3) approximately 400 families caring for both children and adults received respite care; and 4) 267 families caring for children under the age of 18 were served througha a Medicaid waiver; an another 100 families, who do not have Medicaid status, received information and referral services.

Eligibility Criteria: 1) Parent Subsidy Aid is available to natural, adoptive, or foster parents of individuals of all ages with mental retardation or developmental disabilities who without the subsidy would not remain in the home. Gross income for natural parents cannot exceed 400% of the Federal Poverty Guidelines; 2) Early Intervention Services are available to children from birth to three years of age with a developmental disability or a possible developmental disability; 3) Waivered services are available to families who meet the qualifications of both the Division of Retardation and Developmental Disabilities' and the Medicaid Waiver; and 4) Respite care is also available to families who are not on the Medicaid Waiver who are caring for a mentally retarded or developmentally disabled family member.

Services Covered/Allowable Expenditures: 1) Parent Subsidy Aid: Families participating in the program must agree to a General Service Plan which includes a description of how the subsidy is intended to be used; 2) Early Intervention Services are outlined in the Individual Family Service Plan and can be both home and center-based; these services include: education, nursing, psychology, physical and occupational therapy, speech development, counseling, and social work; 3) Waiver services include homemaker services, assistive devices, home modifications, case management, respite care are authorized at six month intervals in accordance with the General Services Plan; and 4) Respite Care can be provided either in or out of the home.

Limit on Benefits to Individual Families: 1) Parent Subsidy Aid: maximum payment is $75 weekly; 2) Respite Care: Fees for respite care for families not on the Waiver are based on a sliding scale. For those on Waiver, there is a limit of 90 hours of respite for a six month period; and 3) Waivered services cannot exceed the cost of placement in a Medicaid funded facility.

Current Funding Level: 1) Parent Subsidy Aid: $330,000; 2) Early Intervention Services: $1.5 million; 3) Respite Care: $312,000; 4) Assistive Devices and Minor Home Modifications (through Waiver): $200,000; 5) Homemaker/Home Health Aid Services: $800,000; 6) The 1989 legislation establishing an Office of Family Support has made an additional $225,000 available in expanded services for families caring for adults with mental retardation; and 7) the 1989 General Assembly has also approved a $1 million bond referendum for grants to families for home remodeling.

Background: In the early 1970's Rhode Island, in response to pressure from courts and advocates to correct problems with the state's institutions, began to develop community based services. In the late 1970's there was a strong grassroots support by parent groups for the creation of the cash subsidy program. The initial purpose of the Parent Subsidy Aid Program was to assist families in bringing a son or daughter home from a state institution. The program has evolved to include families who are at risk of placing a family member outside the home. In addition, Rhode Island has made substantial use of its Medicaid Community and Home-Based Waiver to fund services which support and enhance family care.

Program Structure: The stated purpose of family support services is to enable individuals with mental retardation and developmental disabilities to live at home with their families. Support services are available from the Division of Retardation and Developmental Disabilities and from other state agencies with whom DOR/DD has interdepartmental agreements. The Rhode Island Division of Retardation and Developmental Disabilities contracts with private agencies to provide services.

Parents are involved in the design of services through their participation in the development of the General Service Plan or Individual Family Service Plan. At a policy level, parent representatives serve on the state Advisory Commission on Early Intervention, the regional Special Education Advisory Committees, the Developmental Disabilities Planning Council, and the state Interagency Coordinating Council for PL 99-457. Parents are involved in service delivery through the state's Association for Retarded Citizens (ARC); Rhode Island has a particularly strong ARC which runs many of the state's local programs for adults.

As evidenced by steadily increasing allocations for services, the state's commitment to family support continues to grow. However, support and services for families are still inadequate to meet all needs. Because of limited funds, there is no outreach for the Parent Subsidy Aid program.

Implementation Issues: A major issue in service provision has been the lack of dollars; the state reports a need for significantly more respite care, the Subsidy Aid Program has a waiting list of 40 families (if the state advertised the availability of the service, the number would be much greater). Many families are not eligible for those support services funded through the Medicaid Waiver. Assistance to families who need major home modifications is difficult to come by; the Housing Authority can provide some monies for this, but most Rhode Island families are not income eligible for their help. Voters' support of the $1 million bond referendum could provide significant help to families in this area.

A second issue of major concern is the availability of appropriately trained individuals who can provide family support services. Personnel seems to be in short supply in several areas with nurses, homemakers, and home health aides being especially difficult to recruit.

Medicaid Policy: Rhode Island has made significant use of the Medicaid Community and Home-Based Waivers to offset the cost of family support services. Since 1983 the Division of Retardation and Developmental Disabilities has used Medicaid Waivers to fund homemaker services, assistive devices, minor home modifications, case management, and respite care. Rhode Island also has a Katie Beckett Option. The state's Department of Health has recently been granted a Medicaid Waiver to fund services for technology dependent children. Information about Medicaid may be obtained from: the Medicaid Program Director, Department of Human Services, 600 New London Avenue, Cranston, RI 02920, (401) 464-3575.

Related Efforts

The Department of Health. Through its Medicaid Waiver funded **Case Management Program**, this Department provides services to 50 families who have technology-dependent children. Services available to these families include: information and referral, counseling, in-home nursing care, and opportunities to connect with other families. Another program funded by the Department of Health is the **Home Care Program for High Risk Infants**. Located at Women's and Infant's Hospital, this program coordinates the medical, nursing, social, and health care needs of infants who are being discharged from the Neonatal Intensive Care Nursery. In 1989, the legislature provided $150,000 to the Health Department to provide family support services to families who have infants and toddlers in the Department's **Maternal and Child Health Programs**. For information about services funded through the Department of Health contact: Division of Family Health, Rhode Island Department of Health, 75 Davis Street, Providence, RI 02908, (401) 277-2312.

Office of Special Education. Rhode Island has mandated special education services from ages 3 through 21. Children who have severe and profound handicaps are eligible for educational services on a 230 day a year schedule. For additional information contact: Office of Special Education, Rhode Island Department of Education, Roger Williams Building, 20 Hayes Street, Providence, RI 02908. (401) 277-3505.

Interagency Coordinating Council. Work being done in Rhode Island through the implementation of PL 99-457 includes: the piloting of integrated day care for infants and toddlers with disabilities; development of an expanded service directory for parents; and creation of transition models from early intervention to school. Information about these activities can be obtained from: Thomas Kochanek, Executive Director, Interagency Coordinating Council, Office of Special Education, Rhode Island College, Providence, RI 02908.

The Department of Children and Their Families. In 1989, this Department initiated **Project "Early Start"** to address the needs of at-risk infants and toddlers and their families. The legislation establishing the program specifies an array of prevention and intervention activities to be provided by "Early Start". For additional information contact: Early Start Program, Department for Children and Their Families, 610 Mt. Pleasant Avenue, Providence, RI 02908.

Evaluation: Rhode Island has been one of the first states to move to a community based system of services. It may be the first state in the union to close its state institution for the mentally retarded. The state's Parent Subsidy Aid program is one of the most flexible methods of supporting families who are caring for a family member with disabilities. For more than a decade the state has been increasing its allocations for family support services. The use of Medicaid dollars to support and enhance family care is another example of the state's commitment to families. However, even given this, there is still substantial need for increased services and support for Rhode Island families caring for a family member with disabilities.

Services to families in Rhode Island are provided through a number of state agencies. Rhode Island's service system can be both confusing and complicated, making it difficult for families to find the services and resources they need. While many agencies have a case management component, this typically accesses only those services provided by the host agency. There needs to be improved collaboration and coordination among state and local agencies serving families. If the system hopes to maintain service continuity and quality, the turn over in personnel providing respite, in home care, and other family supports will need to be addressed. Finally, Rhode Island's ability to meet the needs of its families caring for family members with disabilities will require substantially increased funding for services.

Future Directions: Two current planning activities will provide recommendations to the Governor and Legislature concerning future direction and funding of services to families and children. Recommendations will be forthcoming from: 1) the Part H Project for Handicapped Infants and Toddlers under PL 99-457 and 2) a research project being conducted by the Rhode Island Developmental Disabilities Council on how to best meet the needs of families caring for children with severe disabilities or chronic illness.

Parent and advocacy organizations within Rhode Island have expressed a continued commitment to work towards improved support for families caring for children and adult family members with disabilities.

The Governor has established a Children's Policy Coordinator's Office to promote coordination of state policies which have an impact on children.

Lessons Learned: In order to promote and develop family support services, the recommendations coming out of Rhode Island call for increased parent awareness at the grassroots level coupled with information and training to parents on how they can effectively do legislative advocacy. For family support to succeed on a systems level, families, providers, and state administrators must be united in their efforts.

Materials Reviewed

Early Intervention and Family Support Services Brochures, Rhode Island Department of Mental Health, Retardation, and Hospitals.

Parents' Handbook, The Early Intervention Program, Rhode Island Department of Mental Health, Retardation, and Hospitals, October 1988.

Rules and Regulations Pursuant to Chapters 40.1-1-10.1, Rhode Island General Laws as Amended, Parent Deinstitutionalization Subsidy Aid Program, Department of Mental Health, Retardation, and Hospitals, November 1984.

Rules and Regulations Pursuant to Chapters 40.1-22-32 and 42-35, Rhode Island General Laws as Amended, Early Intervention Program, Department of Mental Health, Retardation, and Hospitals, November 1986.

Description of Respite Services, memo Division of Retardation and Developmental; Disabilities; General Laws of Rhode Island for Parent Subsidy Aid and Early Intervention.

Human Services Research Institute's Rhode Island Proposal, 1988; H.S.R.I.'s Summary of Rhode Island Family Support Services, 1985.

SOUTH CAROLINA

Name of Program: Family Support Stipend (FSS)

Nature of Program: Budgeted

Administering Agency/Contact Person: Department of Mental Retardation, Judy Johnson, PhD., Deputy Commissioner, (803) 737-6445, or Joan Hummel, Assistant Deputy Commissioner for Client Services, (803) 737-6481.

Type of Program: Cash subsidy, and direct services provided by County MR Boards.

Number of Families Served: Approximately 220 families received the FSS. More families are excepted every year.

Eligibility Criteria: An individual with mental retardation (IQ < 70) or related disability with similar adaptive level is eligible for services from the County MR Boards. Families who care for member at home and require assistance beyond the Board services may qualify for the FSS. No restrictions based on age. A financial need must exist which takes into account the family's income and expenses of the disabled member.

Services Covered/Allowable Expenditures: The County MR Boards provide such services as mental retardation training and support groups, case management services, diagnosis and evaluation, genetic counseling, community based therapy services, home modifications, EI services, summer camp, extended care services, and respite care. (Not every family receives the FSS.)

Limit on Benefits to Individual Family: Services are based on need. Families who receive the FSS get up to $200 per month in 6 month allotments. A one-time request for up to $500 is available for expensive items.

Current Funding Level: FY 1988: $220,000 for FSS; (this figure will double for FY 1989-90). FY 1989-90: $36,703,000 was spent for community based services, support services, developmental health services, day services, and residential services.

Background: The DMR's County MR Boards and community-based services have been evolving over the last ten years with the push away from institutional care.

South Carolina has 41 County MR Boards which then report to four regional centers. The FSS program is administered through the regional centers. The FSS began as a pilot project several years ago and became a permanent, statewide program three years ago. Family support is seen as a high priority in the state. The goals of family support are to support the family in the care of the person with mental retardation in the community and prevent inappropriate out-of-home placements.

Program Structure: The FSS is available throughout the state. Persons with mental retardation are referred to the County MR Boards from a variety of sources. Until recently the diagnosis of mental retardation was strictly followed. Now persons with related disabilities are eligible for services. The coming year the FSS will also include persons with other developmental disabilities.

South Carolina's respite care program has received support for community-based services in recent years. Prior to 1985, a person with mental retardation could only receive respite care in one of the regional institutional settings. Since that time 85 respite care projects have been developed in 15 regional CM Boards. Respite care is not yet available statewide. However, South Carolina has a 5 year plan which includes the expansion of respite care to statewide coverage.

There are two types of respite care programs: 1) in-home (hourly or overnight care provided in the person's home); and 2) licensed care (hourly or overnight care provided in care giver's home). Rate differentials are dependent upon level of care. To be eligible for respite care, a person must be a client of DMR and have respite care identified as a need in his/her service plan. Families are allowed 27 days per year with many exceptions made for emergencies. There is also a foster care program which provides extended respite care. The budget for the respite care program was $541,124 for FY 88-89 and $552,721 for FY 89-90. In FY 88-89, 2,583 individuals received respite care.

In South Carolina energies are focused on making the County MR Boards more autonomous and on developing community resources. The programs and services are flexible and attempt to meet the individual needs of the family. Approximately 9000 people received community based services, support services, developmental health services, day services, and residential services from the County MR Boards. Approximately, 1000 are on a waiting list for these specific services but continue to receive case management services.

South Carolina seems to be developing a solid family support program which is supported by a network of community resources.

Implementation Issues: Families eligible for the FSS meet with their case manager and must submit identified needs for approval. They receive up to $200 per month in a six month lump sum and are expected to spend the money according to the agreed-upon plan. Exceptions are made and larger sums may be given to families to help pay for costly items, e.g. specialized equipment.

South Carolina does have a statewide case management system. Case management services are provided at the County MR Boards. Directors of case management meet to coordinate services from county to county.

Not enough funds are available to meet all the needs of the clients. Generic services are used whenever possible and case managers develop and promote the use of community resources. DMR has asked the legislature for increased funding. In the past, the DD Council funded a case management system. The purpose was to concentrate efforts on people who were not getting services from other agencies. The funding lasted for ten years; clients were referred to the County MR Boards as of July 1, 1989. DMR continued to provide services to these individuals with partial funding from the DD Council.

South Carolina's history of family support is relatively recent. The Department has been able to demonstrate to the legislature that the dollar amount was minimal, but the benefits of keeping people in their homes were maximal. South Carolina is making progress and demonstrates growth in the area of family support.

Medicaid Policy: South Carolina has a Medicaid waiver for technology dependent children and a waiver for long term community care to prevent nursing home placement of people with mental retardation who are 18 years or older. This second waiver covers such services as personal aides, homemaker services, and respite care. In addition, Medicaid services are offered to all pregnant women, infants and the elderly who are up to 100% above the poverty level. The contact person for these programs is Gwen Power, Health and Human Services, (803) 253-6100.

Related Efforts

Department of Health. Services are not yet in place for 0-2 yr. old children. South Carolina is developing the implementation plan for PL 99-457. The contact person for these activities is Eve Bogan, Department of Health, (803) 737-4050.

The Department of Education. This Department is expected to begin special education services for 3-5 yr. old children. Presently only children who are visually or hearing impaired receive services.
Contact persons: Bob Black or Mary Ginn, (803) 737-8710.

The Department of Mental Health. This Department has a special program for persons with autism which provides parent training and respite care services.

South Carolina statewide referral and information system. To access social and health resources: 1-800-922-1107.

Evaluation: It was reported that parents do not play a major role in the developing and planning of services at the state level. The Departments of Mental Health and Mental Retardation have the greatest input from consumers. The Department of Mental Retardation is the most advanced department in the state with respect to family support.

In general, parents have been pleased with the family support program and have reported that they would not have been able to function without the services, especially respite care.

Future Directions: South Carolina hopes to improve the family support program by developing support groups and family networks, increasing funding, and developing more employment opportunities for adults with mental retardation.

Lessons Learned: It is crucial to involve families at the policy and development level of a family support program. The state should start with decisions that effect family life.

Materials Reviewed: None

SOUTH DAKOTA

Name of Program: South Dakota has no family support services per se, very limited services may be available to families through the developmental services system.

Nature of Program: NA

Date of Implementation: NA

Administering Agency/Contact Person: Thomas Scheinost, Division Director, Division of Developmental Disabilities, Department of Human Services, Kneip Building, 700 Governor's Drive, Pierre, SD 57501, (605) 773-3438.

Type of Program: NA

Number of Families Served: NA (No statistics on families served are kept by the state's Division of Developmental Disabilities).

Eligibility Criteria: NA

Services Covered/Allowable Expenditures: NA

Limit on Benefits to Individual Families: NA

Current Funding Level: South Dakota has allocated no monies for services directed to families.

Background: South Dakota's Division of Developmental Disabilities contracts with private non profit agencies for services, approximately 2,000 individuals are in South Dakota's developmental service system. Services provided include: case management, habilitation, supported employment, and residential programs. The state has two institution's with a combined population of 400. Per capita, South Dakota ranks in the top ten of states who have persons with developmental disabilities living in institutions. However, the state is also rated second highest in the nation with individuals with developmental disabilities residing in community living alternatives under 15 beds. Currently, the state has no waiting list for its developmental services; there is a question, however, concerning whether individuals are receiving the most beneficial or appropriate services.

Program Structure: NA

Implementation Issues: South Dakota is a large (77,047 square miles) rural state, with a total population of approximately 709,000. The state's low population density must be taken into account when planning services for families. In addition, the state currently does not have an effective means for interagency collaboration. Because the needs of families often cross agency lines of responsibility, the lack of coordination and collaboration must be resolved before the state can hope to adequately address family issues.

Medicaid Policy: South Dakota currently has a Title XIX Community Based Care Waiver, services for about 900 individuals are funded through this waiver. South Dakota is investigating the possibility of applying for a Katie Beckett Option for individuals who are chronically ill or emotionally disturbed. No action has been taken to date. Contact person on Medicaid issues is: Dr. Ed Campbell, Division of Developmental Disabilities, Department of Human Services, Kneip Building, 700 Governor's Drive, Pierre, SD 57501, (605) 773-3438.

Related Efforts

Interagency Coordinating Council. Through PL 99-457, South Dakota has an interagency coordinating council examining issues affecting children 0-3 and their families. This group is currently investigating the expanded use of Medicaid dollars to serve this population. Contact person for these activities is: Dr. Dean Meyers, Section for Special Education, Kneip Building, 700 Governor's Drive, Pierre, SD 57501, (605) 773-3678.

Children's Mental Health Services. This agency has a small pilot project underway to expand in home services to families with emotionally disturbed children. Information about this project can be obtained from: Dianne Weyer, Division of Mental Health, Department of Human Services, Kneip Building, 700 Governor's Drive, Pierre, SD 57501, (605) 773-3438.

Evaluation: South Dakota is currently at a crossroads in its service system. The Division of Developmental Disabilities recognizes the need to improve and revise its provision of services. The state has received an outside evaluation of its service system from Gary Smith and Robert Gettings of the National

Association of Mental Retardation Program Directors (NAMRPD). Smith and Gettings stated in their final report that "There are broad, serious gaps in services to families and children in South Dakota ... With respect to services for families, there is clearly no distinct program designed to meet family needs on a consistent and reliable basis. Funding streams appear to be biased toward out-of-home services rather than maintaining the continuity of family life." To address these deficiencies, NAMRPD recommended, "Over the next two years, the State should initiate steps to create a family support program,... with the objective of having a family support program in operation by the beginning of FY 1990-91."

To assist them in revamping their service system, the South Dakota Division of Developmental Disabilities is receiving technical assistance from Syracuse University. Hopefully, the state will follow the guidelines provided in the Smith and Gettings' report and create a service system more responsive to families and consumers.

Future Directions: The state is currently examining its developmental services system and has appointed a Statewide Strategic Planning Group for Developmental Disabilities to assist in the revision of the current system. This 23 member group has strong parent representation; 4 parents, representing parent groups have been appointed, an additional 3 parents, representing other concerns, also sit on the Planning Group.

Lessons Learned: Too soon to say.

Materials Reviewed

Smith, Gary and Gettings, Robert (1988). An Assessment of Services to South Dakota's Citizens with Developmental Disabilities. Alexandria, Virginia: National Association of State Mental Retardation Program Directors.

TENNESSEE

Name of Program: Family Support Program (FSP)

Nature of Program: Budgeted

Date of Implementation: FY 1988 (Jan. 1, 1988)

Administering Agency/Contact Person: Department of Mental Health and Mental Retardation, Jan Lusk-Owens, Coordinator of Family Support and Preschool Programs, (615) 741-4230.

Type of Program: Family Support Services in Tennessee provides services on a contractual basis or Authorization to Vendor (ATV) process. Funds do not go directly to families.

Number of Families Served: Fifty-nine families were served in FY 1988.

Eligibility Criteria: A person with mental retardation who lives with his/her natural/adoptive family or legal guardian. There are no restrictions for age or income. Families are served based on need.

Services Covered/Allowable Expenditures: Specialized equipment/ supplies, sitter services, respite services, specialized nutrition and clothing, adaptations and modifications of equipment and vehicles, child care and other services identified by the families.

Limits on Benefits to Individual Families: The FSP provides up to $3600 per person in services and or goods each year to the family. These funds will not affect eligibility to other benefits such as SSI, Medicaid or food stamps.

Current Funding Level: FY 1988, $108,000; FY 1989-90, $120,000.

Background: The FSP in Tennessee is in its beginning stage. The goals of the program are to reduce stress and prevent costly out-of-home placements. The state recognizes the additional burdens and challenges encountered by families who have members with mental retardation. The focus is on the entire family and not just the individual. "These services represent a belief in the importance of the natural family and they are clearly directed at family preservation and reunification."

The FSP is a state wide program although availability of services varies from region to region. There are three developmental centers, one in each region and each center has a family support coordinator who oversees the program. Families work with a case manager and individual service plans are developed jointly.

Outreach activities also varied from region to region, but information about the program quickly became available and waiting lists for service occurred. Families are served based on need. Family Support Review Committees in each region determine (priorities) families to be severed.

Program Structure: The State of Tennessee is divided into three regions; East Tennessee, Middle Tennessee, and West Tennessee. Each region received an equal share of the $108,000 (or $36,000). It has recently been increased to $40,000 per region. This figure represents 100% state funding.

"A family is eligible to receive services and goods from the program if (a) the family has an individual with mental retardation whom the parent(s) want(s) to keep at home or to be returned from an institution or other out of home placement and (b) the parent(s) will be able to take care of the individual at home if financial, physical or other barriers are reduced or eliminated and adequate community support services are provided. The parent is a parent, guardian legal custodian or a person acting in the place of a parent but does not include a foster parent or any other paid provider. Individuals enrolled in this program are also eligible for the other funded services, with the exception of residential or foster care". Additionally the diagnosis must include mental retardation. There is no restriction on age or income.

Case management is seen as a vital component to providing comprehensive and cost efficient services. Funds may be used for a variety of goods and services with few restrictions. Traditional services include but are not limited to specialized equipment and supplies; child care/sitter services; speech, physical, and occupational therapies; respite care; information and referral services; and Behavior Management.

Funds will not cover costs of supportive services and goods covered through other funding sources. Existing community resources/programs will also be explored as an option.

Implementation Issues: The FSP offers a range of traditional services to families who care for a member with mental retardation. Respite care is the most frequently requested service.

Funds are extremely limited and case managers along with the families are faced with prioritizing the most demanding yet attainable need. In some instances families were given priority for a one time expenditure such as a piece of equipment or home modification over a chronic or ongoing service such as behavior management. Families in stress and in need of respite care were given priority over individuals who need more habilitative services. Those services may be available through other resources.

A second issue that needs to be resolved is the stipulation that the regional centers may only contract with non profit agencies and service providers. This makes obtaining some services very difficult such as a wheelchair from vendors who are for profit. The department is in the process of revising this administrative ruling to allow more flexibility.

This issue is related to the fact that there are restrictions as to how the monies are spent and the justification needed for approval of services. The program needs to be expanded financially to include more people and (offer more choice of services) a greater variety of services.

Finally the program is in its pilot stage. Thirty families were to be served the first year. This number was expanded to 59 families which is still way below the number of families that need services. Waiting lists exist in all three regions, and it is unclear when services or additional funding will become available to them.

Medicaid Policy: The state of Tennessee has a 3 yr. Medicaid Waiver (1986-1989) to cover community services for adults (18 yrs. or older) with mental retardation. Thus far 523 people were served. The state requested a five year extension.To receive service under this program, the person must be eligible for Medicaid and receive Supplemental Security Income (SSI). Eligible services include case management, habilitative services and respite care for individuals who are in Therapeutic Foster Care.

Tennessee also has a Model 50 Waiver for children under the age of 18 who have specialized medical needs. They may be eligible for home modifications, personal care, and case management services. The contact person for the Medicaid Waivers is Jewell Wharton, (615) 741-4228 or 4230.

The Family Support Program and Medicaid Waivers (adult and Model 50) are separately funded and administered.

Related Efforts

The Department of Education. This Department will be organizing an interagency council with representatives from the state agencies along with educators and parents to collaborate on the early intervention services.

The following departments/contact person/and phone numbers are available to discuss family support efforts in their respective departments:

Department of Education: Sarah Willis, (615) 741-0062.

Department of Mental Health and Mental Retardation: Dwayne Doidge, (615) 741-3708.

Department of Human Services: Pat Overton, (615) 741-5927.

Department of Health (MCH): Dr. Wendy McCarthy, (615) 741-7366 or Judy Womack, (615) 741-7353.

Evaluation: Currently there is no formalized evaluation process in place. The informant expressed a need for a Family Support Task Force which could assess the need for services and oversee their delivery statewide. Families do have the right to appeal services. They have input into the development of the Family Service Plan and must agree on the proposed services. Appeals are handled at the regional level and no major problems have occurred thus far. Quality Assurance occurs at the provider/vendor level who must meet certain standards in order to contract with state.

In summary, the Tennessee Family Support Program is presently a small scale project which recognizes its own limitations in terms of services offered and the number of families receiving services. The families that have been served have benefitted from the relief they provide and the assistance that would otherwise be unavailable.

Future Directions: Improvement in the program will be determined by the expansion of services and the number of families being served which can only occur with additional funding. Families need more flexibility and freedom in spending money and arranging for services.

Lessons Learned: The FSP has proved to be cost-effective, and this will continue to be its greatest source of support.

Materials Reviewed

Family Support Authorization for Direct Purchase for Family Support Services Allotment Code 339.23, FY1989-90 (3-page description of services and allowable expenses).

Family Support Plan (Executive Summary, no date).

Medicaid Waiver: for persons with mental retardation (brochure from the Department of Mental Health and Mental Retardation including three regional offices, addresses, and phone numbers; a description of the adult waiver program).

Community Skills Profile (booklet used by the Department to assess individual needs and determine appropriate placements for people with mental retardation).

1-page Waiver update of the three regions and number of slots (4/89).

TEXAS

Name of Program: In-Home and Family Support Program

Nature of Program: Legislative mandate

Date of Implementation: 1988

Administering Agency/contact Person: There are two programs with essentially the same purpose and general model of services in two separate state departments

Department of Human Services (TDHS)	Department of Mental Health and Mental Retardation (TDMHMR)
Linda Lamb	Liz Shelby, Carol Lee Moore
512-450-3199	512-323-3256 512-323-3170

Type of Program: Cash voucher program, the TDMHMR has been experimenting with the debit card program and has a debit card system.

Number of Families Served: There were 2,217 applications for services and funds allocated to 1,246 individuals and families in the MHMR part of the program in 1988 and 1,192 out of 1,856 applicants in 1989 and approximately 45-47 served in the pilot.

Eligibility Criteria: The TDMHMR program serves persons with mental retardation, mental illness, autism and children under 4 who have developmental delays. The TDHS administers a permanent program targeted to provide services to people with disabilities not covered under the TDMHMR program. The TDHS program requires people to have a physical or mental disability and at least one functional limitation. Applicants to both programs with an income level at or below the Texas median income are eligible without co-payment, those above are eligible with a co-payment.

Services Covered/Allowable Expenditures: These programs are flexible and offers almost anything the family requests including health services, counseling and training programs, home care such as respite, attendant care, housekeeping services, transportation, architectural modifications plus a variety of things such as clothes, furniture, household supplies, and the purchase or leasing of special equipment. The only designated limitations are payment for abortions, payment of past bills, back taxes on homes and funeral expenses.

Limit on Benefits to Individual Family: Individuals qualifying for the program can receive up to $3,600 annually for services as well as a one time grant of $3,600 for architectural modifications to their residence or for special equipment, or "other capital expenditures."

Current Funding Level: TDMHMR: 1990, $3.5 million; 1991, $4.5 million (mental retardation, 0-3, autism); 1990, $2 million (mental illness); TDHS: 1990, $2 million; 1991, $4 million.

Background: The program was developed and implemented in response to the request of consumers of mental health and mental retardation and developmental disability services, their families and some advocacy groups. Input from these individuals was sought through five public forums which were followed up with work groups who in turn developed the framework for the program.

The Texas In-Home and Family Support Program was created in 1987 through a House bill. The program is administered by two state agencies, the Texas Department of Mental Health and Mental Retardation to which $6 million was allocated over a biennium. The Texas Department of Human Services was directed to develop a pilot program to which no state funds were appropriated. But the sum of $315,000 was allocated by the Texas Rehabilitation Council on behalf of the Texas Planning Council for Developmental Disabilities each year of the biennium. The pilot program was limited to one county.

In the legislative mandate, a co-payment schedule was established. Vouchers are issued only under conditions that those involved agree to provide receipts documenting how the money was spent.

In 1989, the Texas legislature amended the In-Home and Family Support program with a bill that established a permanent program at TDHS for people with disabilities who have at least one functional limitation and do not meet the eligibility criteria for TDMHMR In-Home and Family Support services.

Program Structure: The overriding goal of the In-Home and Family Support Program in Texas, is to enable persons with disabilities to purchase services which support them in living as independently as possible in their communities. The program operates on the following principles: That persons with disabilities should be assisted in living in situations similar to those of persons without disabilities; that the value of the family is to be upheld and recognized as the primary support system in a person's life; and finally, that persons with disabilities are to be encouraged to select services and providers.

To determine the availability for the program, the individual seeking services or their family, contact their mental health or mental retardation authority who then verifies whether the person is eligible for the program. Their income level is then evaluated to determine the amount of co-payment they will make. A written plan is developed presumably reflecting the need, services, provider, amount of co-payment, who will be paid, the rate, the frequency and total amount to be paid.

Within the mental health and mental retardation side of the program, two sites are run on a debit card system in which the family receives a card that they can use with vendors who have been pre-determined. The co-payment is determined by a sliding scale with the base for full compensation set at the Texas median income level. The majority of individuals served, however, are below the Texas median income.

The program is administered on a local level through the community-based component of the agencies. There is a local project coordinator in the Department of Human Services program and project coordinators in the

Department of Mental Health and Mental Retardation component of the program. They act in an advisory capacity, but parents maintain a great deal of control over services.

Quality control issues are basically the responsibility of the family. A survey of consumer response to the Family In-Home Support Program, indicated a high degree of satisfaction.

TDHS is in the process of converting the pilot project into a regular TDHS program.

Implementation Issues: The program has not been highly publicized in the state with most families finding out about it through local and area Mental Health and Mental Retardation centers. From the outset, there was an awareness that there would not be enough money in any community to completely meet the potential need.

In FY '88 approximately 971 of the individuals or families that applied for family support services did not receive any. In the first quarter of '89 approximately 664 applied and did not receive services.

In conjunction with program an advisory group was formed which initially brought people together around family support issues. In the state, there is increased talk about the need for interagency cooperation. Many state agencies appear aware of the need to provide services and funds across agencies, but movement in this direction is slow.

Medicaid Policy: The Texas Medicaid program includes several of the services potentially covered by the family support program. In the eligibility determination process for the In-Home and Family Support program, the service provider (MHMR, TDHS) is required to determine if the applicant is eligible to receive services from other support programs. There is a Katie Beckett waiver used in the state as well as some Title XX funds for primary home care, but the latter is very medically oriented. For further information on Medicaid, call and request name of contact person from: Betty Hable, Central Office Coordinator in Department of Human Services, 512-450-3197

Related Efforts

Education. Contact: Jill Gray, 512-463-9414.

Health. Some efforts here related to chronically ill children. Contact: Pam Farley, 512-458-7111, extension 7355.

Evaluation: It appears that the State of Texas has taken some very positive steps toward a comprehensive family support program that is focused on meeting the needs of individuals and families. As the program expands throughout the state, a major challenge will be maintaining flexibility. The steps toward family support seem to have been well-thought out and the legislation demonstrates both commitment and an understanding of the family support model.

Some concerns worth noting are the debit system and the lack of control some families may feel in response to pre-determined vendors. The use of a co-payment system may prevent some individuals from even applying for services.

Trusting the families to make their own decisions has been a strong point of the system. Parent surveys of the program have shown a high degree of satisfaction.

Though the program appears to be stable, fiscal issues are always of concern especially as the program looks to expand. The possibilities for exploring other financial options while maintaining flexibility remain a central challenges.

Future Directions: The future looks good from a public policy standpoint. The legislature has an understanding of the program and has been very supportive of it's development to date.

The state appears to see funding as an important element related to the future expansion of the program. There is a possibility of looking to the Medicaid waiver to provide some further funding options in the state, though only 25% of people living below the federal poverty level qualify for Medicaid in the state.

Though there are many people living in the community settings without services, the State of Texas also maintains a large institutional population which must be addressed in the future. In the state, the majority of funds go to the institution, so the family support program must be approached from the standpoint of diverting people from institutional placement and avoiding high future costs, rather than as a direct attempt to close the institutions.

Lessons Learned: It is important to have an understanding of a variety of options before going to the legislature. This, as well as having broad-based support when approaching the legislature were important factors. Starting small and looking at incremental increases was a useful posture in the State of Texas.

The availability of a developmental disabilities grant to begin the project and an advisory group made up a variety of individuals were major contribution to the beginning of this program.

Materials:

House Bill 1154: Authorizing legislation for program, effective 9/1/87.

Senate Bill 982: IHFS for Persons with Disabilities as approved effective 9/1/89.

Texas In-Home and Family Support Program, Report to the 71st Legislature. Texas Department of Mental Health and Mental Retardation and Texas Department of Human Services with Texas Planning Council for Developmental Disabilities, February, 1989.

UTAH

Name of Program: Family Support Services

Nature of Program: Budgeted

Date of Implementation: 1987

Administering Agency/Contact Person: Department of Social Services, Division of Services to the Handicapped (DSH) Contact: Marilyn Bowan, 120 North 200 West, #201, Salt Lake City, UT 84103, 801-538-4200.

Type of Program: Services

Number of Families: 50-60 families given individual grants, 200-300 given respite services, 100 recreational services.

Eligibility Criteria: Individuals who have a handicapping condition and who are three years of age or older and in need of family support. There are no income eligibility criteria although they are talking about the possibility of a sliding fee scale in the future.

Services Covered/Allowable Expenditures: Respite care, homemaker care, personal attendant care, nursing health aides and limited medical supplies and services, nutritional counseling and care, psychiatric therapy, speech and hearing, physical and occupational therapy, behavior management, parent training and counseling, limited provisions for adaptive equipment, other services that are identified in an assessment.

Limit on Benefits to Individual Family: Ranges from $60 - $5,000; the average requests are around $2,000.

Current Funding Level: $447,100

Background: Family Support Services in Utah began with respite services which provided hourly and overnight care of people with disabilities. In 1985, approximately $24,000 was allocated so that families could receive help to maintain their family member at home. This was done through small contracts with providers.

In the first year of the program, a variety of services were provided as well as communication devices, homemaking, attendant and nursing care. The program was found to be beneficial in diverting several individuals from institutional placements. It was available in all areas of the state.

In 1988, the financial resources to the program were expanded. The State of Utah also offers a state income tax incentive for families to keep their children at home.

Program Structure: The primary objective of the Family Support Program in Utah is to avoid or delay institutional placement and encourage and assist families in staying together. The program itself is made up of several components: Direct Family Grants, which must be applied for annually and only cover those services and needs not obtainable through any other service networks or funding. These services are intended to be short-term interventions and not long-term programs; however, in some case longer term care may be approved if requested.

Respite, designed to provide intermittent, time-limited care to individuals and to enable parents and caretakers to gain relief from the parenting. Respite can take place in the family home by a trained provider, in special respite care homes and in institutions. Social-recreation describes recreational opportunities at camps (e.g., Western Adventures Ranch), bowling, as well as transportation to and from such events. This is available only to those individuals residing at home or in other supported living arrangements. Finally, the Utah State Life Support Skills Counseling for families offers family counseling and training.

Entry into the system is through a serparate statewide case management programs. If there is a need for a service that was not covered under any of the other areas of accessibility, a special request form is written up by the case manager and the family. A needs assessment application is filled out and a contractor is determined who will supply the additional services. Records are maintained on each client receiving services as well as a log as to when services were received, describing the needed service as well as the amount of money requested. Respite services, however are more limited and determined by certification through the state.

The program is administered out of the central office, but there has been an attempt to move the administration to a regional level but lack of staff made this difficult.

Implementation Issues: The program has become a popular one in the state and knowledge of it has spread through word of mouth, advocacy groups and case managers. There has been no active outreach.

The service is being sought by an increasing number of families. At this time, there is not an active waiting list, and the state feels it is serving most of the requests it receives, although some individuals are not given as much as they request. The program is seen as flexible by most families.

At this time, there is not a great deal of interagency coordination. There have been some public meetings held by the DD Council to inform parents of what is available, and to invite input for the state plan.

Medicaid Policy: The Medicaid waiver is used very minimally in the State of Utah for family support services. Only two families were put on waivered services this past year. For further information on Utah's use of the Medicaid waiver, Contact Mr. Jerry Jackson, Associate Director, Department of Social Services, Division of Services to the Handicapped, 120 North 200 West, #201 Salt Lake City, UT 84103, 801-538-4200.

Related Efforts

Education. There have been some very aggressive attempts here related to moving children (3 and up) and supporting them in community schools. Contact: John Killaron, (801) 538-7708.

Mental Health. Some attempts may have begun and small grants applied for related to family supports but this was not clear. Contact: Gary Jenson 801-538-4270.

Health. Efforts through a grant working with ages 0-2 to assist technology dependent children. This agency has been designated to work with early intervention issues. Contact: Chris Kaminski, 801-538-6922.

Family Services. Program oriented to getting children back into their homes. Contact: Bill Ward, 801-538-4084.

Evaluation: One strength Of the Family Support Program in Utah appears to be the degree of flexibility that the family has in defining their needs and the control they are able to exercise.

There are certain aspects of the Program (respite), that appear to be much more controlled by the system, yet there is also a sense that if a family wanted to choose neighbors, for example, as providers, the system would be open to this as long as they were certified. Though the system seems to listen to the families' and caseworkers' requests, there may be some danger of losing this receptivity as the program centralizes. People in the state seem to be aware of this and are looking at decentralizing and creating more local control. Further organization of parent coalitions and lobbying efforts are essential.

A strong guiding set of principles would better enable the program at a state level to define direction and the nature iof the program's commitment to families.

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Future Directions: It is likely that the program will expand, and that there will be an increase of funds. The legislature appears very open to family-centered programs. Growth also brings the fear that with any large program there will be a loss of flexibility.

There has been some discussion concerning an alternative systems that would put more control in the hands of the family through by giving them complete control over cash subsidies.

Lessons Learned: It is very important to go into such a program with a great deal of flexibility, having parents define the services that they feel are needed.

In working with the legislature it is important for parent coalitions to play a central role in winning such support.

Materials Reviewed

Department of Services to the Handicapped, Specific Standards, Family Support Services.

Department of Services to the Handicapped, Specific Standards, Respite Care.

Family Support Services, A statement on the beginnings of Family Supports.

Drafts of the following:

Family Support Services (1/88), Services to the Handicapped Manual, Section III-G.

Socialization and Recreational Programs.

Standards for Respite Care Services (4/16/89).

Standards for Respite Care Services (8/88), Services to the Handicapped Manual, Section VIII.

Utah Department of Social Services, Policy for Individual Family Support Services (4/16/89).

VERMONT

Note: This was the one state where our informants gave us very extensive information on programs with a major focus on families of Children needing mental health services.

Name of Program: 1) Intensive Family-Based Services; 2) Respite Care

Nature of Program: Intensive Family Based Services and Respite Care for persons with mental retardation are on-going state funded programs. Respite Care for children with mental illness is a new federally-funded demonstration project.

Date of Implementation: Respite Care for persons with mental retardation began in 1976. The respite demonstration project for children with mental illness will be operational in October of 1989.

Administering Agency/Contact Person: 1) Intensive Family-Based Services: Ann Pugh, Department of Social Rehabilitation Services, 103 South Main Street, Waterbury, Vt. 05676, (802) 241-2131; 2) Respite Care for persons with mental illness: Sherry Schoenberg, Vermont CASSP, Child and Adolescent Service System Program, Division of Mental Health, 103 South Main Street, Waterbury, Vt. 05676, (802) 241-2621; 3) Respite Care for persons with mental retardation: Theresa Wood, Division of Mental Retardation, 103 South Main Street, Waterbury, Vt. 05676, (802) 241-2614.

Type of Program: 1) Intensive Family Based Services provides families with in-home services, 2) Respite Care:

Number of Families Served: 1) Intensive Family Based Services: 131 families; 2) Respite Care: 50-100 families are expected to be served in the first year by new respite grant through Division of Mental Health; 3) In FY 1989, approximately 400 families received respite services through the Division of Mental Retardation.

Eligibility Criteria: 1) Intensive Family Based Services: This program primarily serves families whose children (under the age of 18 or if still in public school, up to 21) are severely emotionally disturbed; issues of abuse and neglect, parent-child conflict, sibling conflicts, and other problems threatening the maintenance of the family unit are also considered. 2) Respite Care by the Division of Mental Health the individual receiving respite must be severely emotionally disturbed. 3) Respite Care by Division of Mental Retardation, the individual must be mentally retarded; there is no age or income eligibility criteria for this service. Infants and toddlers who are severely delayed or at risk of being delayed can also receive respite services.

Services Covered/Allowable Expenditures: 1) Intensive Family Based Services: including: crisis intervention, basic skill training, counseling, assistance in using community resources, and information and referral; 2) Respite Care: temporary care in or out of the home.

Limit on Benefits to Individual Families: 1) Intensive Family Based Services: Intervention with the family is typically for a three month period, with an average of 10 hours a week spent with the family in their home; 2) The Respite Care program through the Division of Mental Health is just being put in place; they expect to establish a sliding fee scale for families; 3) Respite Care through the Department of Mental Retardation allows families to use 264 hours of respite at no fee. Families arrange their own respite care and are reimbursed for respite up to minimum wage, $3.65 an hour. If state funding is available, families can be reimbursed for up to 800 hours of respite on a sliding fee scale. .

Current Funding Level: 1) Intensive Family Based Services: approximately $2 million; 2) Respite Care: through a federal grant to the Division of Mental Health: $200,000; 3) Respite Care: through the Division of Mental Retardation, $544,150.

Background: Vermont CASSP (Child and Adolescent Service System Program), funded through a grant from the National Institute on Mental Health, is in its fifth and final year. The planning and interagency collaborative efforts of CASSP have resulted in increased and improved services to Vermont's youth who are emotionally disturbed and their families. The 1988 System of Care Plan submitted to Vermont's General Assembly influenced increased appropriations to Vermont's Intensive Family Based Services. In 1989 the legislature increased funding for three existing programs and funded programs in the three regions of the state which had previously been unserved. A federally funded demonstration respite grant for children with severe emotional disturbance, grew out of CASSP findings that respite care is the number one priority for families.

Vermont's Division of Mental Retardation was the first state agency to establish a respite care program. In recent years, the Division's support to families has been growing; from FY 1989 to FY 1990 the Division of Mental Retardation increased funding for services directed to families by more than 40%.

Program Structure: The Department of Mental Health, through its Divisions of Mental Health and Mental Retardation, is the state agency responsible for overseeing services to the state's citizens with mental illness and mental retardation. Service programs are administered at the local level through Community Mental Health Centers. When a child is at risk of removal from the home because of abuse and neglect, the Department of Social and Rehabilitative Services becomes involved.

1) Intensive Family Based Services are funded statewide through the Department of Social and Rehabilitative Services. This service is primarily short term, up to three months, intervention with families for the purpose of improving the specific behaviors or conditions that put the child(ren) at risk of removal. The service focuses on stabilizing the family and connecting them to other support services. It is the goal of the program to preserve or restore family unity and to empower families to take control of their own lives so that they can function effectively and independently. The family and service worker establish goals to improve the stability of the family. Services, provided in the family's home and community, are individualized to meet each family's specific needs. In Vermont this service has resulted in a reduced number of out-of-home placements for children.

2) Respite Care: The Division of Mental Retardation has offered statewide respite assistance for over ten years. The program primarily provides financial assistance; families must secure and pay their own respite providers and are reimbursed for the service. (See Limits on Benefits section for greater detail). Only one of the state's ten Mental Health Centers has a list of respite providers available to families. In addition to the reimbursement for respite, the state contracts with three respite care families for out-of-home care. These homes may be used by families for vacations or emergencies; respite care provided by one of these homes is not subtracted from the family's annual allocation of respite hours.

3) Respite Care being set up through Division of Mental Health's demonstration project uses a significantly different service model. Important components of this project are the recruitment, training, and matching of respite providers and program evaluation. The program hopes to generate a group of qualified respite providers, at the local level, who are interested and capable of providing temporary care for children with severe emotional problems.

Implementation Issues: 1) Intensive Family Based Services: While this program has been effective, there remain a number of families in need who are not being served. CASSP estimates an additional 190 Vermont families could benefit from Intensive Family Based Services. The degree of sophistication and effectiveness of this program varies somewhat from region to region. There needs to be a greater degree of pre-service and in-service training for family workers. In addition, families need better access to long-term support services once their involvement with Intensive Based Family Services is over.

2) Respite Care: This service as offered by the Division of Mental Retardation has increased the number of families served from 163 in 1980 to over 400 in 1989. While respite services have grown, they are not adequately funded; an official in the Division estimates there are easily twice as many families who could benefit from the service than are currently receiving it. Because dollars for this service are limited, there is minimal outreach or promotion of the respite care program. Additional problems with this service include the inability of some families to locate their own respite provider; finding qualified care givers is especially difficult for families caring for a family member with a behavior problem or complex medical needs. For some families paying up front for respite care is a financial burden. To address these and other issues, the Division of Mental Retardation has brought together families, service providers, advocates, and state government in a planning process that is working to broaden future family support services.

Medicaid Policy: Vermont has both a Home-Based and Community-Based Services Waiver, used primarily to fund residential services for individuals leaving institutions, and a Katie Beckett Option. The Disabled Children Home Care Program and the Technology Dependent Program use Medicaid dollars to pay for health care services in the home. Contact person is: Amelia Lessor, Department of Social Welfare, 103 South Main Street, Waterbury, Vt. 05676, (802) 241-2761.

Related Efforts

Department of Special Education. Through PL 99-457, Vermont has an **Interagency Coordinating Council** examining issues affecting children 0-3 and their families. Through a Part H grant, $75,000 has been made available to expand respite services for families with infants and toddlers. Contact person for this activity is: Kim Keiser, Department of Special Education, 120 State Street, Montpelier, Vt. (802) 828-3141.

Department of Social and Rehabilitative Services. Limited respite care is available for foster families caring for children with disabilities. Contact person is: Steve Dale, Department of Social and Rehabilitative Services, 103 South Main Street, Waterbury, Vt. 05676 (802) 241-2131.

The Vermont Health Department. This Department funds respite care for health impaired children. The contact person for this service is Michele O'Neil, (802) 863-7200.

Parent to Parent. This is a parent support and advocacy group for families with a family member with any type of disability. Contact person: Nancy DiVenere, Parent to Parent of Vermont, 1 Main Street, Champlain Mill #69, Winooski, Vt. 05404, (802) 655-5290.

The Division of Mental Health. This department is supporting a new statewide organization to provide support, information and referral, and advocacy for parents of children with emotional illness. For more information contact: Judy Sturtevant, 103 South Main Street, Waterbury, Vt. 05676, (802) 241-2621.

Evaluation: Vermont has made significant strides in addressing the needs of children with severe emotional disturbance and their families. The Intensive Family Based Services are reported to be an effective intervention model for at risk families. It is unclear, however, whether communities or the state can provide the long term supports that families may need. Expansion of the Division of Mental Health's demonstration respite program would provide one much needed form of long term support. Good collaborative efforts on the behalf of this population by agencies at both the state and local levels should help to ensure the provision of needed services.

The Division of Mental Retardation's newly implemented planning process being conducted by the Family Support Services Committee will hopefully result in expanded support and services for Vermont families caring for family members with mental retardation.

Future Directions: The 1988 Vermont Legislature passed Act 264 mandating the development and implementation of a coordinated system of care so that children and adolescents with severe emotional disabilities and their families will receive appropriate educational, residential, mental health, and other treatment services in accordance with an individual plan. The act establishes the means by which to improve the delivery of services by determining who is in charge of the service, by clarifying the administrative process by which they are available, and mandating the participation of the Departments of Education, Mental Health, and Social and Rehabilitative Services.

With passage of this legislation, Local and State Interagency Teams are now mandated as a mechanism for problem solving, service coordination, and planning. These teams are comprised of representatives from the three involved departments, as well as parents of children who have a severe emotional disturbance. Local Interagency Teams are charged with, identifying unmet needs in their catchment areas, making recommendations when eligibility for services is in dispute, attempting to resolve issues concerning service responsibility, and serving as a forum for consideration of general

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issues relating to youth with emotional disturbances. Information regarding local service needs, as well as any unresolved issues, are passed on to the State Interagency Team. The State Team is responsible for developing an annual system of care plan which identifies the number and characteristics of children in need of services, describes services needed, and recommends a plan to meet these needs.

The Division of Mental Retardation is in the beginning stage of examining family support needs. An advisory committee, with strong family representation has been appointed. The Division is hopeful that the work of this committee will result in proposed family support legislation for the 1990 session of the Vermont legislature.

Lessons Learned: The work of the Vermont CASSP established the mechanism to identity and address many of the issues affecting persons with severe emotional disturbance and their families. Their planning and collaborative efforts at the local and state level have now been codified in Act 264. The model that has been created to solve problems of agency responsibility and to plan for service development appears to be an effective one that warrants replication in other areas.

Materials Reviewed

The Vermont System of Care Plan for Children and Adolescents Who Are Emotionally Disturbed and Their Families, Vermont Agency of Human Services and Vermont Department of Education, January 1989.

New Directions, A Newsletter of the State and Local Interagency Teams, Spring 1989 and July 1989 issues.

VIRGINIA

Name of Program: Family Support Pilot (FSP)

Nature of Program: The FSP is pilot project under the Office of Mental retardation budget.

Date of Implementation: FY 86, Jan. 1, 1987.

Administering Agency/Contact Person: Department of Mental Health, Mental Retardation, and Substance Abuse Services (DMHMRSAS). Office of Mental Retardation Services, Shirley Ricks, (804) 786-4130.

Type of Program: The FSP is a combination of support services and reimbursement to families.

Number of Families Served: The first year 56 individuals were served. The second year 165 individuals were served. As of this date 200 individuals have received services.

Eligibility Criteria: "A family shall be eligible for the program if: a family member has either mental retardation or mental illness and is a client of DMHMRSAS; the person lives at home with his/her natural or adoptive family; and the needed service cannot be obtained at no charge from some other source." All ages are served and there is no restriction on family income. However, individuals most in need of services receive priority.

Services Covered/Allowable Expenditures: A variety of services have been provided to families such as respite care, behavior intervention, wheelchairs, van lifts, leg braces, communication boards, dental care, ramps, stairway lifts, eye glasses, incontinent supplies, household supplies, adaptive equipment, and bathroom modifications.

Limit on Benefit to Individual Family: $3,600 per year.

Current Funding Level: $350,000 for two years.

Background: The impetus for a family support program started in 1981 when a task force composed of parents, central office staff, institutional staff, and mental health consumers met to develop a family support program in Virginia. Several years later in 1985, Human Services Research Institute was awarded a federal grant to study and design a program to support family care for persons with developmental disabilities. The results of that study provided the incentive for the Secretary of Health and Human Services to target funds for a pilot which three pilots received funding.

The goals of the projects are to improve and enhance the quality of life available to a person with a mental disability by strengthening the family's capability to care for their family member; to make it possible for families to choose to have their family member with mental disabilities remain in, or return to the home; to support, to the extent possible, people with the most severely disabled and their families; and to ease the day-to-day demands on families.

Program Structure: The Commonwealth of Virginia has 40 Community Service Boards (CSB) that provide comprehensive case management and social services to persons with mental retardation, developmental disabilities, and mental illness. Three CSBs were selected by the Commissioner of the DMHMRSAS to be the pilot sites for the family support program. Some CSBs have started a family support program with local funds. The state money was not divided equally among the three project sites but rather was allocated based on population, size of client case load, and need.

The program is individualized and flexible, and parents are given an opportunity to identify their own needs. The role of the case manager is to help families obtain needed services through already existing programs as a first option, or purchase services with FSP money as a second option.

Implementation Issues: The FSP of Virginia serves people with mental retardation and mental illness. The program has received some criticism from advocates and family members of people with physical disabilities to expand the definition of disability.

The services are broad and comprehensive, and to that extent, families are not limited in their choice or options. The most frequently utilized services of the list on the first page are: equipment, respite care, behavior intervention, and home modifications.

There is no charge to families for services with the exception of one pilot which uses a sliding fee scale for respite care. This particular project has the widest range in family income, and it was thought a sliding fee scale would make the service more equitable.

Families who are on a waiting list for family support services are given priority based on specified criteria. Unlike some of the other states, whose waiting lists are either handled on a first-come-first-serve basis, or whose waiting lists are left up to the discretion of the case managers, Virginia has stated priorities. For some support services: "Priority consideration will be given to persons under the age of 21 with severe or multiple handicapping conditions; persons who are on waiting lists for admission to state institutions or community services; persons who are away from their family home but would be able to return if supports were in place; persons whose fiscal resources in relation to the costs of needed services are insufficient; and single parents or other types of families with limited resources to provide care."

Medicaid Policy: At the present time Virginia does not have a community based waiver program for persons with mental retardation. A waiver is being developed by Stan Butkus in the DMHMRSAS, (804) 786-4130.

Virginia does have a personal care waiver for the elderly. The contact person for the program and State Medicaid is Charlie Carnes, Program Coordinator, Medical Assistance Services, (804) 786-1465.

Related Efforts. Family supports in Virginia are in their initial phase and other agencies are just beginning to address issues relate to family care. The DMHMRSAS is very involved in developing the Individual Family Service Plan (IFSP) for P.L. 99-457. The contact person is Mike Fehl, (804) 786-1746.

Evaluation: The FSP is limited in the sense that it is a pilot program and not available state wide. Because of its pilot status a lot of paper work has been done to monitor funds and document the program's effectiveness.

Quality assurance activities consist of collecting biannual reports and statistics, and conducting annual family satisfaction surveys. Families have been satisfied with the program and feel it has provided them with a better quality of life in a more normalized way. This is the first time assistance of this nature has been available.

The program could be improved by 1) reducing the paper work which would free up time for the case managers, and 2) expanding the program statewide.

Parents need to be more involved in the planning and developing of services. Currently they have a weak role at the state and local level.

Future Directions: Virginia is on the way to developing a solid family support program. The DMHMRSAS is developing a state policy for family supports and hoping for permanent status of services. They plan to bring it up for legislation in the near future. Family support is becoming well-recognized and will be able to hold its own weight in competing for resources.

Lessons Learned: Virginia has started its family support system through the use of pilot projects. "Departments of Mental Retardation should not wait for major funding. They should start small if they have to. Even small scale projects can be used to demonstrate effectiveness." The departments must get parents involved and build a political constituency.

Materials Reviewed

Virginia Family Support Project; Final Report on the Family Support Program, A Pilot to Assist Families with Their Mentally Disabled Family Member at Home. Virginia DMHMRSAS, 1988 .

WASHINGTON

Name of Program: Family Support Services

Nature of Program: The program is now permanent contained in the aregular budget and written into Washington Administrative Codes (WACs).

Date of Implementation: The movement toward family supports actually began in 1972-73 under the name "Home-Aid Program" and tried to provide help to families in preventing out-of-home placement. The program had maintained and grown over the past years. A court case, two years ago, mandated the state to assure that there had to be some uniform way to respond to parents' requests is a major impetus behind the program today.

Administering Agency/Contact Person: Department of Social and Health Services, John Stern, Department of Social and Health Services, Olympia, WA 98504-0095.

Type of Program: Services

Number of Families Served: Approximately 2,500 families receive some sort of service through the program annually. This figure does not necessarily indicate on-going support services.

Eligibility Criteria: Service eligibility is based on Washington Administrative Code, which defines developmentally disabled as including mental retardation, cerebral palsy, epilepsy, autism, auditory impairment, visual impairment, or a condition closely related to mental retardation or one that requires similar level of treatment.

Services Covered/Allowable Expenditures: Services include but are not limited to emergency or planned respite care (80% of funds go for respite); attendant care; therapeutic services (physical therapy, occupational therapy, behavior management therapy and communication therapy); the purchase, rental, loan or refurbishment of specialized equipment; environmental modifications; and other adaptations. Individual requests are permitted at the discretion of the director of the individual region.

Limit on Benefits to Individual Family: Services are time-limited and based on monthly service authorizations. Monthly authorizations are based on service requests and service priorities, determined by need levels designated in the WACs.

Current Funding Level: $2.5 million in FY 88. Figures show a breakdown of funds are as follows: $2 million to respite; $327,000 to attendant care; $162,000 to therapy; $55,000 to equipment; and $32,000 to transportation.

Background: In 1974, the State of Washington started what was called the Home-Aid Program whose basic intent was to provide help to families in order to prevent out-of-home placement of their child with a disability. Until the mid 80s there was much regional discretion in how money was spent. The led to a class action suit in 1987 related to the denial of services to some individuals. A Supreme Court ruling mandated that there must be a statewide, uniform way of responding to parents' requests for services. Budgets are now handled in central offices rather than regions, and there is a great deal of uniformity across the state.

Program Structure: The goals of the program as stated in the Washington Administrative Codes are "to reduce or eliminate the need for out-of-home residential placements of clients wherein the in-home placement is in the person's best interests." It is also to allow consumers to live in the most independent setting possible, and to have access to services best suited to the person's needs.

Involvement in the program begins with parental contact with a caseworker; together they establish a list of priorities related to the needs of the family. Each regional office has a family support services review committee which reviews requests as well as the case manager's recommendations for services. They also determine individual service authorization levels based on the Washington Administrative Codes. Requests are established for a fixed period of time, up to six months. New requests must be completed or existing requests modified whenever there is a change in the type, duration or amount of service being requested. Service needs have been divided into levels in the Washington Administrative Code and funding is used based on the determined level of need. Authorizations for services are then sent to the family, indicating the amount for services they are authorized to receive and the designated time. Families themselves are never involved in the transaction of finances.

There is a right to an administrative review and appeal as designated by the Washington Administrative Codes for families that feel they were unjustly refused services. Families are often required to make requests on a monthly basis, which is sometimes disruptive and creates an experience of uncertainty.

Annual meetings of committee members from all regions are held to review policy and to increase consistency of the responses to requests. Central office staff annually conduct reviews of all the regional offices. Limited parental input exists regarding quality control issues. Outreach and dissemination regarding the family support services are not apparent; rather, information is passed through word of mouth.

Implementation Issues: Eligibility issues are described in the Washington Authorization Code guidelines. Of major concern are those individuals who may be deemed a level 3 or 4 in terms of need which places them in a low priority category. Their wait for support is long and they often give up on the application process. The system is now largely directed by professionals. To over come this the department has begun looking at the model of families as their own case managers.

Attempts at interagency planning are being made regarding children's services through a Governor's initiative for a statewide conference. There remains a need to increase parental involvement in such efforts.

Medicaid Policy: There is presently little being done with waivers in the State of Washington. There are some Title XX and Title IX funds being used. For more information related to Medicaid, contact: Tim Yowell, 206-753-4425.

Related Efforts

Division of Mental Health. There have been some efforts with limited funding: A pilot was set up to allow parents to make annual requests to determine how much money they would need on an annual basis to support their child at home. Contact: Dennis Olsen, 206-586-3526.

Children, Youth and Family Services. This agency is in the process of searching for family support initiatives. Contact: Katherine Brian, 206-586-4031.

Developmental Disabilities Planning Council. Others having information related to family supports in the State of Washington include this agency. Contact: Sharon Hansen 206-586-3526.

Evaluation: It appears that those receiving family supports in the State of Washington are satisfied with the services. The following problems are unresolved: 1) an undetermined number of people receive services; 2) the application process discourages families; 3) the state may be losing track of the total need that exists; and 4) uncertainty regarding the continuation of funds continually confronts families.

Through governed by a court mandate, each regional area does maintain some discretionary abilities. More extensive parental input appears to be vital to the future of family supports in the state. Washington appears to be moving toward dveloping ways to increase family control. Idea under consideration include vouchers, cash subsidies and shifting money to more local control.

Future Directions: The Division of Mental Retardation Services may divide families into two groups for the purpose of funding options: those who require extensive supports and those who do not. The use of vouchers to provide to families with more autonomy has been discussed as the basis for small pilot projects. There is an effort under way to assist families in networking with each other.

Lessons Learned: It is important to start with a philosophy within the state service system that has an emphasis on supporting families. The notion of promoting flexibility allows parents to make decisions. Local control and planning as well as a community-based orientation is something that the state is striving for.

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Materials Reviewed

State of Washington Administrative Code, Amend Washington Administrative Code 275-27-220 Family Support Services, Amend Washington Administrative Code 275-27-4000 Notification, New Washington Administrative Code 275-27-213 Service Priorities.

State of Washington Administrative Code, Definitions: Eligibility for Services; Determination of Eligibility Amending Washington Administrative Code 275-27-020,030: New Washington Administrative Code 275-27-026.

Policy Statement, Family Support Services, Division Policy Directive #546. February 1, 1989.

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WEST VIRGINIA

Name of Program: West Virginia does not have a family support program.

Nature of Program: NA

Date of Implementation: The state of West Virginia is providing community based services in part because of the Medley Consent decree in 1981. Comprehensive Community Behavioral Health (CBH) Centers started in the 70's.

Administering Agency/Contact Person: Department of Health, Office of Behavioral Health Services, Jim Green, (304) 348-0627.

Type of Program: Direct services are provided to individuals with developmental disabilities by the CBH centers, nonprofit agencies contracted by the state.

Number of Families Being Served: The Office of Behavioral Health Services does not keep a count of persons who received services. Statistics are kept at each of the local centers. Three hundred and fifty people have been served by the consent decree.

Eligibility Criteria: Any individual who has a developmental disability according to federal guidelines is eligible for services through the Office of BHS. Services are based on need and not on family income.

Services Covered/Allowable Expenditures: Services include but are not limited to nutritional management, speech, occupational, and physical therapies, counseling, and respite care.

Limit on Benefit to Individual Family: Services are based on need. Every eligible individual receives at least some service.

Current Funding Level: For FY 1989 West Virginia spent $12 million on DD/MR budget. This includes all services provided by the CBH centers. Budget is not separated into services provided to individuals living with natural families v. individuals living in community/out-of-home placements.

Background: The state of West Virginia is divided into 14 service regions each having its own designated Comprehensive Community Behavioral Health Center including some satellite offices. The CBH centers are nonprofit agencies contracted by the state to provide the case management services as well as the other direct services.

Community services developed in part because of a 1981 consent decree to deinstitutionalize individuals with mental retardation who were in the institution longer than 1 month or who were 23 years or younger as of 1979. The aim was to return children to the community first. Since 1981, 400 individuals have been relocated back into the community. Initially the class action clients received priority in the delivery of services, but now everyone is for the most part treated equally and services are delivered based on need.

The goal of the program is stated simply: to provide comprehensive community care.

Program Structure: As in other states who contract independent providers for community based services, West Virginia's system offers a lot of discretion and variability.

People generally find out about the program through advertisement and word of mouth. Each individual and or family meets with an interdisciplinary team to identify their needs. The services attempt to be family driven. The families should have an equal partnership with the professionals. The programs discourage package services and emphasize services that are flexible and meet the needs of the individuals.

The CBH centers provide case management services, nutritional services, speech, occupational, and physical therapies, counseling, respite care, minor home modifications and early intervention services. Most of the EI services have an in-home component. Respite care has grown financially but it still is very limited and informal.

Implementation Issues: While efforts to expand and coordinate services are underway, much work lies ahead for West Virginia to develop a family support system. Programs have waiting lists and services are not available in all regions. Families do not pay for services, but wherever possible insurance is billed. Each year, centers are allotted so many new slots, and the class action clients receive priority for the waiting list, although every person receives at least some kind of service. There is a right of appeal that works rather quickly. A hearing and determination is made in 30 days.

Medicaid Policy: West Virginia has in many ways utilized the Home and Community Based Waiver to its fullest potential. It has been able to supplement services that are lacking in the community and CBH centers.

The FY 1989 budget for the Medicaid Waiver is $7.6 million. Of this amount, $685,000 is for residential rehabilitation which can be used to pay parents directly for providing care. West Virginia was one of the first states to use the Medicaid waiver to pay families for services. When the waiver was first approved it was aimed at individuals coming out of the institution. On the

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second and third approval, funds became available for family care. Services provided by the waiver include nursing care, respite care, transportation, home modifications, and therapies.

In FY 1989, 324 people were served by funds from the waiver. Fifty-two percent were children and youth and 91% of them lived with their natural families. There are 100 individuals on the waiting list for the waiver; 75% live with their family and are under 23 years of age

In general the Medicaid waiver in West Virginia makes it possible for many individuals to live in the community, the majority of whom live with their natural families. Approximately 100 individuals are expected to come into the waiver program this year.

The Medicaid waiver also reimburses community/out-of-home placements. West Virginia is rapidly expanding their residential care facilities to accommodate the normal exit from family life. They are limiting the bed size and have funded 47 6-8 bed units for residential care and 3-4 bed units for individuals who need more intensive care.

Finally there is an effort underway to coordinate the case managers from the CBH centers with the case managers from the Medicaid waiver to provide continuity of services.

The contact person for the Medicaid waiver program is Jim Green, (304) 348-0627.

The Department of Human Services has a Medicaid Waiver aimed at preventing nursing home placements of the elderly. The individual must be over 60 and at risk of an out-of-home-placement. This waiver does serve some elderly individuals with developmental disabilities.

Related Efforts: West Virginia is one of the nation's poorest states, yet it is moving toward a diverse service system.

The Department of Human Services. This Department has an adoption subsidy program with a monthly stipend of $420 per month to families who adopt a child with special needs. The Department contact person is Daisy Clark, (304) 348-7980.

Foster Grandparent Program. DHS also offers this program for children with developmental disabilities, some of whom live in residential or institutional settings. The program's contact person is Ann Adkins, (304) 348-0627.

The Department of Health. This Department is responsible for coordinating services for children with special medical needs. The program's contact person is Dr. Mary Scanner, M.D. or Phyllis Higley, (304) 348-5388.

The Office of Behavioral Health Services. This office is responsible for early intervention services. Currently they are working on implementing PL

99-457 and are developing the individual family service plan. The EI programs are experiencing problems with transition into the Department of Education, which has minimal services. The contact person for EI is Barb Merrill, (304) 348-0627.

The Developmental Disabilities Council. This organization has funded 3 demonstration projects for respite care, one of which focuses on care for persons with autism. The contact person is Julie Pratt, (304) 348-0416.

The state of West Virginia has 55 school districts, 23 of which have parent resource centers. These centers aim to provide training and advocacy for parents and educators regarding the special education process and obtaining services. It is hoped that these centers will stimulate the Education Department to provide comprehensive services.

Evaluation: West Virginia does not have a well-developed or coordinated family support service system. The services that are minimally provided are directed toward deinstitutionalization but not necessarily toward family-centered care. The informant reported that in a recent study, 97% of the services in one rural county are delivered to family homes. Conversely, 90% of the services delivered in the more populated areas are provided in group homes and other residential facilities.

The state is attempting to change the direction of services and is encouraging family input. Monitoring of services is a priority for the state: the Office of BHS conducts utilization reviews, annual site visits, and medical reviews. There are 15 family care specialists and independent advocates assigned to attend the team meetings. Also the local Departments of Health visit the clients.

Of the families who receive services, there is satisfaction with the quality and kind of service offered. The programs in part have been able to keep families intact.

The limitations of the program are still many. The state is unwilling to fund families for direct care or reimburse for out-of-pocket expenses. Additionally, the CBH centers have difficulty in locating, training, and retaining qualified staff.

Future Directions: West Virginia hopes to expand its services to include a larger number of families and develop an intake process which moves more quickly.

Lessons Learned: It is crucial to involve politicians in order to develop a family support system. Legislation needs to be reformed: as it stands now, the Medicaid waiver still encourages out-of-home care, although in community residences. The focus needs to be directed toward family centered care.

WISCONSIN

Name of Program: Family Support Program (FSP)

Nature of Program: The FSP in Wisconsin is legislated by State Statute, s.46.985 and Administrative Rule HSS 65.

Date of Implementation: FY 1984

Administering Agency/Contact Person: Department Of Health And Social Services, Beverly Doherty, Division of Community Services, Developmental Disabilities Office, (608) 266-7469.

Type of Program: The program provides case management and flexible funding for families to purchase goods and services identified as needed in each family's individual service plan. At the request of the family, the agency may pay providers directly or may pay families to reimburse for services.

Number of Families Served: In FY 1989, 1,300 families were served.

Eligibility Criteria: To be eligible for the FSP a child must be between the ages of 0-21; have a developmental disability and live with his/her natural or adoptive family.

Services Covered/Allowable Expenditures: Funds may be used for a wide range of services and goods based on the individual needs of each family. There are fifteen broad service categories (see program structure).

Limits on Benefits to Individual Families: Up to $3,000 annually may be used per disabled child. There is a provision to waive the maximum when funds are needed and available.

Current Funding Level: The FSP was funded at $1,971,000 for FY 1989 in 47 counties. This includes 10% for case management and other administrative expenses, but excludes county matching revenues.

Background: Wisconsin's FSP is intended to ensure that ordinary families faced with the extra ordinary circumstances that come with having a child with severe disabilities will get the help that they need without having to give up parental responsibility and control.

The program began in 1984 as a demonstration project of the Wisconsin Council on Developmental Disabilities. Aided by a favorable evaluation of the project and broad grass roots support for widening the availability of family support services, legislation was passed in 1985 to authorize family support as a permanent program. Since 1984, the number of counties participating in the program and the dollars available for services has grown steadily. By 1991 almost $3 million will be available in all 72 Wisconsin counties. Still the $3 million represents less than half of what is projected as needed for full program implementation.

In 1985, a method for projecting county by county and statewide costs for the program was developed. The funding formula is based on factors which include numbers of children in each service area, a prevalence of severe disabilities rate that was derived from public school data, and an average payment per family. The formula is useful in providing solid information to analysts and legislators during budget deliberations and has been used by advocates to argue for additional funding to serve families on waiting lists for the program.

Program Structure: Wisconsin's FSP provides funding to families to purchase supportive services and goods not covered through other funding sources. The program is based on the belief that parents of children with severe handicaps know their needs and those of their child. For this reason, and because of the individuality of each family, goods and services available through the program have been very broadly defined, leaving considerable leeway for families to choose whatever will help maintain the child in their home. Any service or any portion of a service, that is documented as needed in a family's service plan and that is approved by the administering agency may be funded, up to $3000 per year, depending on availability of funding.

Services or goods requested by families generally fall within the following categories: 1) architectural modifications to the home; 2) child care; 3) counseling and therapeutic resources; 4) dental and medical care not otherwise covered; 5) specialized diagnosis and evaluation; 6) specialized nutrition and clothing; 7) specialized equipment and supplies; 8) homemaker services; 9) in home nursing and attendant care; 10) home training and parent courses; 11) recreation and alternative activities; 12) respite care; 13) transportation; 14) specialized utility costs; and, 15) vehicle modifications. Additionally, the program can pay for the costs of other goods or services as approved by the state. For example, funds have been used to purchase a washer and dryer and pay for lawyer fees.

Counties may choose to use up to 10% of the Family Support allocation to cover administrative costs which, for this program, include staff time for case management services. Medical Assistance (MA) may also be used to recover some of the cost of case management for many eligible families.

While the family is considered the service recipient, eligibility for the program is dependent on the presence in the family of a child with severe disabilities. A disabled child is one who is physically, mentally or emotionally impaired and is, or is likely to be, substantially limited in being able to perform at least three of the seven functions of daily living, among which are mobility, learning, self care and self-direction. The child must be under the age of 21 and living in the family home. The age limit may be waived, however, for young people between 21 and 24 years who are transitioning from school to adult services. While there is no limit on family income, a cost sharing plan is used to determine a family's share in the cost of services and supports received.

A family may be headed by a biological or adoptive parent. A special provision of the Family Support program provides an advance payment to a family to prepare for the return home of the eligible family member who is residing in a public or private institution or other type of out-of-home care.

Implementation Issues: Family Support will be implemented by January 1991 in all 72 Wisconsin counties. However, the funding level at that time will cover only about 42% of the families in need in most service areas. As a result, families are often underserved or may remain on waiting lists.

Outreach activities are conducted through a variety of contacts with schools, hospitals and parent-to-parent. The success of the system ultimately relies on a good social service and case management system and a broad network of supports. The professionals who work with the families must be able to assist them in identifying their needs and help them to access community resources.

Medicaid Policy: Wisconsin's Medical Assistance benefit package is one of the most comprehensive in the country. Anyone who is eligible for Aid to Families with Dependent Children (AFDC) or Supplemental Security Income (SSI) is automatically eligible for MA. If the parent's income and resources make the child ineligible for either of these programs there is still the possibility that a child may obtain Medical Assistance through the Katie Beckett program. The child must require a level of care in the home that is typically provided in a hospital, skilled nursing facility or intermediate care facility. The cost to the Medical Assistance program for home care must not be greater than institutional care. The child must be 18 yrs. or younger. Currently the program assists over 2000 children.

The contact person for the Katie Beckett program is Sylvia Bailey, (608) 266-9590, Bureau of Long Term Support.

Wisconsin also has a number of Medicaid Home and Community Based Waiver programs, two of which are important sources of assistance to children. The Community Integration Program 1A (CIP 1A) may be used for children and adults returning to their home communities from one of the states' three centers for the developmentally disabled. The Community Integration Program 1B (CIP 1B) serves individuals with developmental disabilities who are returning from nursing homes (other than state centers) or who are being diverted from nursing home placement. The Waiver programs, CIP 1A and CIP 1B, provide an even broader array of services than those available through the basic benefit package. Services may include, for example, respite care, home modifications, and vocational services.

The contact person for the CIP 1A and CIP 1B programs is Robin Cooper, (608) 267-9741, Developmental Disabilities Office.

Related Efforts

The Department of Public Instruction. This is Wisconsin's lead agency for the **Program for Children With Special Health Care Needs**, under Title V of the Social Security Act. A contact person for that program is Gene Miller, (608) 267-7148.

The Maternal and Child Health Programs. The contact for these programs is Gareth Johnson, (608) 266-2670.

The Office of Mental Health. This office has recently begun an initiative to assist families whose children have emotional disturbances. With the assistance of a grant from the Robert Wood Johnson Program, the **Child/Adolescent Services System Project** is being piloted. The contact person is Eleanor Mclean, (608) 266-6838.

The Department of Health and Social Services. This Department is Wisconsin's lead agency for implementing PL 99-457, Birth to 3, early intervention services. Contact people in the department are Sue Robbins, (608) 267-3270, Division of Community Services and Susan Tillema, (608) 266-3822, Division of Health.

Evaluation: In Wisconsin parent advocacy and support played an important role right from the beginning in developing and securing the Family Support Program. There is a statewide Advisory Committee with provider and parent representatives. Additionally, each county that has a FSP is required to have an advisory committee with more than 50% family representatives. The responsibilities of the committee are to monitor the program, provide local recourse for families and oversee services and family needs.

In general, the families have felt very positively about the FSP. County staff report that the program is very flexible and easily administered. According to a survey conducted by the State on the FSP, 81% of the families felt that the services provided reduced stress.

Future Directions: While Wisconsin is moving toward availability of the FSP through out the state there is still a major problem of under funding in most counties. The lack of adequate funding has impinged on the program's basic philosophy of flexibility and consumer directedness. Continuing to implement a program which is flexible, individualized, and family-centered is the greatest challenge program providers face. In the past, the service system has focused primarily on supports which could be purchased. The challenge in the future will be a new emphasis on holistic integration of paid and unpaid supports furnished in typical settings, directed by families, and firmly aimed at promoting integration.

Lessons Learned: Several key elements were thought to be important in developing a family support program. The program should ideally have a cash subsidy source or a flexible funding component supplemented with support services. The program should be consumer directed and able to serve all families that meet the eligibility criteria. Finally, the program needs the involvement of families at all levels.

Materials Reviewed

Family Support Program: In-Home Supports and Services to Families Who Have A Child With Severe Disabilities -- Ability to Pay and Grant Size, revised August 1, 1987 (manual prepared by the Department).

Family Support Program: Rationale for County Allocations (no date) (3-page summary of prevalence data).

Family Support Program: In-Home Supports and Services to Families Who Have A Child With Severe Disabilities (no date) (2-page description and purpose of program).

"Wisconsin's Family Support Program", *Families For All Children*, The Center on Human Policy, September, 1987 (1-page article; summary of program).

Family Support Program: Guidelines and Procedures, Wisconsin Department of Health and Social Services, November, 1985, revised December, 1987 (administrative manual and complete description of program).

Medical Assistance for Disabled Children Living at Home (the Katie Beckett Program, Division of Community Services, Department of Health and Social Services, Bureau of Long Term Support, January 1988 (brochure describing program; for public use).

Bureau for Children with Physical Needs, *Information Update*, November 6, 1986, Bulletin No. 86.1, (description of programs and services).

Family Support Program: Allocations 1983 to 1987, (2-page budget report; breakdown by county).

Prevalence of Children with Severe Disabilities in Wisconsin, August, 1986, (report of study conducted by the State of Wisconsin to project amount of services needed).

Focus and Services of the Wisconsin Program For Children with Special Health Care Needs, Wisconsin Department of Public Instruction, Division for Handicapped Children with Physical Needs, (brochure describing children).

The Family Support Program - 1987 (summary of the program: Dane County).

WYOMING

Name of Program: Deinstitutionalization Pilot Project, Family Support Network Project, and private respite services (names not available).

Nature of Program: Pilot/demonstartion

Date of Implementation: NA

Administering Agency/Contact Person: For demonstration and planning projects: Sharon Kelsey, Director, Wyoming Planning Council on Developmental Disabilities, Barret Building, Room 408, Cheyenne, Wyoming, 82002, (307) 777-7230.

Type of Program: Planning project, demonstration project

Number of Families Served: No statistics are available on families who receive respite care through the private sources. Nine natural and foster families will be participating in the deinstitutionalization demonstration project.

Eligibility Criteria: NA

Services Covered/Allowable Expenditures: The demonstration project will provide families with a monthly payment to cover services needed to maintain a child at home. The nature of those services will be decided on a case by case basis. Families will be allowed a one time expenditure to make home or vehicle modifications necessary for them to care for a family member at home.

Limit on Benefits to Individual Families: For the demonstration project it is expected the average family expenses will be $350 per month.

Current Funding Level: Wyoming has allocated no monies for services directed to families. All the funds for this effort come from the Developmental Disabilities Council

Background: The Wyoming State Training School in Lander has 430 individuals with developmental disabilities residing in an institution designed to house 250 people. Those community developmental services available are funded by the state and provided by private not for profit local agencies.

Program Structure: Wyoming has no state sanctioned or funded family support programs. Three Wyoming communities: Cheyenne, Casper, and Rock Springs have privately operated respite care services. Two additional communities are attempting to develop respite care. The Wyoming Planning Council on Developmental Disabilities, in conjunction with the Wyoming State Training School in Lander, has a very small demonstration project to place nine children currently residing in the institution back with their families or with foster families. The Planning Council has recently initiated the Family Support Network Project, the purpose of the project is to identify family needs and to begin planning for services.

Implementation Issues: A severely critical report issued in December 1988 by David Ferliger cited the Wyoming State Training School as failing to provide "minimally adequate" training and habilitation services for residents of the institution. The report cited numerous instances of alleged abuse and neglect, including an alleged sexual assault on a disabled man and a mentally retarded woman allegedly choking to death on vomit. The documented failure of the institution to adequately care for its residents may offer the state a rationale to chose other methods (i.e. family support) of providing services for citizens with disabilities.

The development of services to families must take into account the unique nature of the state. Wyoming is the ninth largest state and the least populous (490,000); lengthy and severe winters can also be a complicating factor in providing services. Furthermore, the Wyoming economy relies heavily on income from energy resources: coal, natural gas, uranium, and oil. This dependence has traditionally meant the state is either in a boom or bust situation. Wyoming is currently experiencing a severe economic downturn; state monies will be hard to come by.

Medicaid Policy: Medicaid dollars are used in Wyoming to improve services at the institution, Medicaid is not used to support community services. Medicaid contact person is: Steve Zimmerman, Division of Community Programs, Hathaway Building, 2300 Capitol Avenue, Cheyenne, WY 82002, (307) 777-6845.

Related Efforts

Interagency Coordinating Council. Through PL 99-457, this state council is examining issues affecting children 0-3 and their families. Contact person for this activity is: John Moses, Division of Community Programs, Department of Health and Human Services, (307) 777-5399.

Evaluation: Wyoming, the Equality State, has a long way to go before its citizens with disabilities or their families could be considered to have equal opportunity for participation in community life.

Future Directions: In August 1989, Wyoming was selected as one of ten states in the nation to receive technical assistance from Human Services Research Institute and United Cerebral Palsy as part of Federal grant to educate policy makers on family support issues. This effort, coupled with the Planning Council's Family Support Network Project, should help the state move closer to understanding and addressing the issues affecting families caring for sons or daughters with disabilities.

Lessons Learned: Too soon to say.

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APPENDIX A:

LETTER DESCRIBING FAMILY SUPPORT PHONE INTERVIEW

Dear

The Administration on Developmental Disabilities recently funded the Human Services Research Institute (HSRI) along with United Cerebral Palsy Associations (UCPA) and the National Conference of State Legislators (NCSL) to examine state family support policy. This project titled "Educating Policy Makers and Empowering Families" will provide families, professionals and policy makers with information regarding states' support for families of people with developmental disabilities.

We felt that given your knowledge of your state's system of services you could provide us with the most comprehensive overview of each state's family support policy. This information will be collected by a telephone interview to be conducted some time between mid-June and the end of August. Your participation will require approximately one hour of your time which will be scheduled at your convenience.

During the interview we will be asking for specific information in the following areas:

1) An overview of your state family support policy and relevant programs including existing laws and regulations, funding levels, and background regarding the genesis of family support efforts in the state;

2) Specific information regarding the individual components (e.g., subsidy, services, respite, case management, etc.) of the family support system including basic program descriptions, current level of funding, eligibility determination, number of families served, flexibility and responsiveness to individual family situations, limitations, amount of required family contribution, genesis of this program, major implementation problems, program administration (centralized, regional, contracts..etc.) and a knowledgeable contact person;

3) Information on the degree to which state medicaid policy supports in-home care and family supports with a particular emphasis on waiver programs;

4) Basic information on the degree to which programs in various state departments (other than DD/MR) including Social services, Health (Maternal & child health, Title V), Child welfare, Mental Health, and Education (PL 99-457) are oriented toward family supports (If possible we would appreciate the name and phone number of a

person in each department who we could contact for more detailed information on these activities); and

5) Your sense of the future direction of family support efforts in your state.

In addition we will be requesting copies of published material which will give us information regarding family support policy and programs in you state. We will appreciate it if you have these material available or can direct us to a source for obtaining them.

On the enclosed form please indicate two times when it would best to contact you. If you feel that another individual within the state can better provide us with this information please forward their name, address, and phone number on the form. Please return the form in the enclosed self-addressed stamped envelop by June 10. If we are unable to accommodate your requests for an interview time we will contact you by phone to arrange another time.

Your answers will be most helpful in completing the project and provide valuable assistance to families and professionals. We look forward to your participation.

Regards,

FAMILY SUPPORT POLICY PHONE INTERVIEW APPOINTMENT

PLEASE RETURN BY JUNE 10

Please contact: ____________________

At this phone number: ____________________

On either: ____________ at _______(Time)

or

____________ at _______(Time)

to conduct the Family Support Policy interview described in the attached letter

IF YOU FEEL SOMEONE OUTSIDE THE DEVELOPMENTAL DISABILITIES COUNCIL WOULD BE A BETTER SOURCE OF INFORMATION ON YOUR STATE'S FAMILY SUPPORT POLICY PLEASE FILL IN THE FOLLOWING:

NAME: ____________________

TITLE: ____________________

ADDRESS: ____________________

____

____

PHONE: ______________

STATE: ________

APPENDIX B:

FAMILY SUPPORT PHONE INTERVIEW GUIDE

FAMILY SUPPORT PHONE INTERVIEW GUIDE

We are attempting to develop a comprehensive picture of the national effort in the area of family supports and provide a resource for states that are only in the initial phases of developing a family support system. So while our primary focus is efforts that fall under the umbrella of Mental Retardation or Developmental Disabilities services we also want to gain some idea of the other efforts in each state which can also support families.

The interview first request a general overview of family supports and some background, we will then discuss the specific of the actual program or services which fit under this umbrella.

1. **Briefly describe Family Supports in your state.** Perhaps as a start you might want to comment on the fact that recent data from the University of Illinois shows that your state spent a total of $______.__ on family supports in FY 1988 and this amounted to __% of your state's MR/DD budget. What falls under this budget category? Does the figure seem accurate?

   * Is there family support legislation? (Can you send us a copy or give us the citation so we can retrieve it).

   * Are family supports a single program in the MR/DD department or is it an effort with multiple components? (e.g., Respite, Support Services, Subsidy or other financial assistance, Case Management, or Others)

   * Is the family support effort statewide or does it entail a great deal of regional discretion?

   * Is it a permanent program or is it a pilot project?

   * Have there been family support pilot which have not led to permanent efforts in this area? If yes why?

2. **Please describe the various components of your state's family support system**. (In states where there are multiple programs--respite, subsidy, services, case management, etc--ask the informant to describe them in order of importance (i.e., positive impact on families). Get parallel information on all programs

Program name______________________________

1. Briefly, what is the origin of this specific program (if different from information already obtained)?

2. What is the funding level of this program in the present fiscal year?

3. How many families receive services under this program

4. What are the stated goals of this program?

5. What type of services/supports does it provide or fund?

6. Briefly describe how the program works

7. What are the eligibility criteria (age, disability, income)?

   * What are the issues/ problems involved with these criteria?

   * Is there a right of appeal?

   * Has there been a wood work effect (more families applying than initially anticipated)? Please explain

   * Is there a waiting list? Please discuss
     How many families are on it:______

   * How do families find out about this program? Is there active outreach to families?

8. To what extent is this program flexible and responsive to the individual needs of families? (i.e., is it a narrowly defined group of service available on a take it or leave it basis or does it really look at what the family needs.)

9. To what extent do the families exercise real control over the planning and delivery of services through this program. If the disagree with professional/provider decisions is there an appeal mechanism.

10. How is the program funded? What are the specific source of funds and your best estimate of the relative contribution of each sources

    * Do family pay anything for this service? How is that determined?

11. Were there problems in the initial implementation of this program and how were they resolved?

12. Currently do you feel there are any major problems with this program. Please discuss and highlight the direction in which you see a solution, if any to these problems.

13. Is this program administered uniformly throughout the state or is there a great deal of regional autonomy. Discuss the relative strengths and weaknesses of this approach.

14. What type of quality control or monitoring is being done?

 * Is it working effectively?

15. What are you general impressions of this program's

 Strengths:

 Weaknesses:

16. What are your suggestion for improvement of this program.

17. In general, what effect has this program had on families?

 * Are families satisfied with the program?

 * What do families like **least** about the program

 * What do families like **most** about the program

18. Where can we get any regulations, policies, evaluations, or public relation material related to this program?
 Who can we call for further information about this program?

3. Have any of the program you just described or has any other effort attempted to **utilize the private sector and generic community services as a component of family support** (e.g., Y's providing recreation or day care, private health insurance, private funding of specialized adaptations, etc.)

4. Is there a effort to develop a **services coordination/case management** component in your family support system? Please discuss, with emphasis on any major issues/problems with such coordination.

5. To what degree **does your state Medicaid policy support families and underwrite home care**. Specifically **describe waiver programs** which are applicable here. Who can we call for further information on Medicaid policy and waiver programs?

6. A comprehensive approach to family supports for all children with disabilities and special health care needs and their families potentially entails a multitude of programs located in many state departments. Please briefly **describe family support efforts which you are aware of in other state departments and** tell us Who can we call about this department's activity

7. Is there any effort underway to address the issues of **interagency cooperation and collaboration** in the area of supports for families?

8. On the state level what role do **parents** play in the **planning, design, delivery, and monitoring** of services to families?

Is this role sufficient? Are there efforts underway to expand this role?

9. What do you see as the **future direction** of family support policy and practice in your state.

10. Based on the experience in your state what **advise** would you give to other states interested in developing family supports.

11. On a regular basis who is the best person for parents to call for information on family supports in your state?

OBJECTIVES

Evaluate the quality of residential services (other than ICF's-MR) provided people with developmental disabilities in Hawaii

Evaluate the adequacy of quality assurance and evaluation activities including case management and staff training

Evaluate the capacity of the system to provide quality services

BACKGROUND

RESIDENTIAL TRENDS--NATIONAL AND HAWAII

1. Deinstitutionalization 1000 > 160: into existing, generic settings: board & care homes 722 & nursing homes 112

2. Specialized programs: group homes 135, foster care 113, small ICF's-MR 70+

3. Individualized arrangements: semi-independent living & supported living

QUALITY ASSURANCE TRENDS
(MIRRORS RESIDENTIAL TRENDS)

1. **Facility-centered licensing: Protection from harm, health & safety**

Conflict with normalization and independence principles

2. **Facility-centered certification: active treatment, reactive (assurance)**

3. **Client-centered: case management, training & TA, proactive (Enhancement)**

QUALITY ASSURANCE MECHANISMS

DOH Licensing of Care Homes & Group Homes:

Nurse and nutritionist surveyors

Emphasis on health, safety & nutrition

Operators required to have extensive nurse training

> "Family-scale nursing homes"

Happy filipino care home operators

Unhappy 'howley' group home operators

Contracting:

Limited monitoring, no enforcement

QUALITY ENHANCEMENT MECHANISMS

Case Management

Lack of community system supports > always in crises mode

Overwhelming paperwork > from field to desk

Minimal training & specialized supports (IDT)

Loss of status & influence with providers & DD authority

Training:

UAP--centralized curriculum

Group homes--limited in-house training capacity

FINDINGS

General:

Residents are physically healthy and safe

Little social and community integration

Little emphasis on resident development and independence

Care Homes:

Isolated operators

Very limited access to specialized supports
(e.g. behaviorists)

Over-use of psychotropics to manage behavior

Group Homes:

Alienated operators

Limited in-house supports (e.g., behaviorists)

CONCLUSIONS

The community based residential service system and quality assurance system in Hawaii remain largely 1st & 2nd generation

The case management system is weak and ineffective

RECOMMENDATIONS

Certify rather than license DD residential programs

Relax some unnecessarily restrictive licensing provisions

Promote the development of mid-size residential agencies able to provide own specialized supports and training (infrastructure)

Impose tighter controls on the use of psychotropic medications

Strengthen and enliven the case management system by reducing the administrative burden, through training, through increased recognition, and by allowing them back into the field to work with residents and providers